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Caring: Influences and Implications

By

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**A thesis submitted in partial fulfilment of the requirement for the
degree of Doctorate of Clinical Psychology**

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May 2004

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List of abbreviations

ABI Acquired brain injury
PTG Post-traumatic growth
PTGI Post-traumatic Growth Inventory
CiOQ Changes in Outlook Questionnaire
GHQ General Health Questionnaire

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Acknowledgements

I would like to thank my supervisors, Dr Delia Cushway and Dr Stephen Joseph who have been supporting me with advice and help from the initial ideas stage through to writing up my thesis. Also thanks go to Dr David Giles for advice regarding my interview study and interview schedule. I would also like to thank all the charities who supported me with recruiting participants, in particular the Coventry and Warwickshire branch of Headway and Coventry Carers Centre. Thanks go to all the participants who took part in my study, especially the women who agreed to be interviewed. Their openness and strength were an inspiration to me.

Also huge thanks go to my family and friends who have given me lots of support and encouragement. The IPA group meetings were much appreciated for moral support and guidance. In particular I would like to thank Helen for her invaluable help by reading my work and Tim for his ongoing support and faith in my abilities. Thank you.

Declarations

This thesis was carried out under the supervision of Dr Delia Cushway and Dr Stephen Joseph who helped me design the study. I carried out the interviews, transcribed and analysed all the interviews. Apart from these collaborations the thesis is my own work. Authorship of any papers from this work will be shared with the above. This thesis has not been submitted for a

degree to any other university. The literature review is being prepared for submission to *Psychotherapy: Theory, Research, Practice, Training* (Deane & Cushway). The 2 empirical papers are being prepared from submission to *Brain Injury* (Chapter 2, Deane, Cushway & Joseph; Chapter 3, Deane, Joseph & Cushway). The reflective review is being prepared for submission to *Clinical Psychology* (Deane). Appendix H contains details of instructions for authors.

Word Count (excluding tables)

Literature Review:	5139
Brief Paper:	3068
Main Paper:	5465
Reflective Review:	1913
Total:	16562

Summary

The majority of literature concerning carers of people with acquired brain injury (ABI) concentrates on the negative consequences. Knowledge of post-traumatic growth (PTG) and positive gain from caring is expanding in the literature. The aim of this study was to explore the experience and report of PTG in carers of people with ABI.

Chapter 2 looked at the self-report of PTG, positive and negative changes in relation to coping and mental health symptoms. The results of thirty-six carers suggest that carers will report at least one positive change as a result of being a carer. However, a stronger relationship between negative than positive changes for mental health symptoms and maladaptive coping.

The experiences of being a wife of someone with ABI were further explored in Chapter 3. Thematic analysis using Interpretive Phenomenological Analysis (IPA) was used to analyse interviews of wives' experiences and report of PTG. The themes identified relate to adjustment, coping and the life domains associated with PTG, in particular to interpersonal relationships and philosophy of life.

Consideration of informal carers led to speculation of the motivations of professional carers, including psychological therapists. A literature review (Chapter 1) was conducted of the empirical evidence describing the

influence of personality and family of origin on choice of career as a psychological therapist. The results are discussed in relation to methodological limitations, clinical implications and future directions for research.

Chapter 4 offers reflections on the process of carrying out research and the impact, particularly of qualitative research, on the researcher. Some clinical implications from Chapters 2 and 3 are expanded to that contained within the chapters.

The past and personality – their influence on caring professions

Abstract

Over the years the motivations, both conscious and unconscious, of a career as a psychological therapist have been discussed. Much of the literature is based on theoretical discussions without supporting empirical evidence. This article reviews existing empirical evidence in relation to the historical and theoretical background. The focus of the empirical studies is mainly on the impact of a psychological therapist's family of origin and personality factors on professional and personal functioning. Whilst the empirical studies do not provide convincing evidence of the prevalence of psychopathology in therapists, the potential impact on therapeutic work is highlighted. Methodological and conceptual limitations of research in this area are discussed in addition to recommendations for clinical implications and future research directions.

1.1 Introduction

Many people choose to pursue a career of professional helping or caring, such as psychologists, doctors and nurses. Literature has widely discussed the motivations, both conscious and unconscious, of pursuing such a career. The aim of this review is to examine that literature by considering how strong the evidence is, and to discuss the implications of the literature for selection, training and support throughout the career of people in caring professions.

Although this review will consider all caring professions, its main focus is on psychological carers, in particular clinical and counselling psychologists, psychotherapists and psychiatrists. The literature in this area is very broad and spans many years, during which time professional roles and theories have changed greatly. The aim of the review is to discuss the historical perspective, bringing together principal discussion articles and landmark studies, then moving on to see how these theories hold up to more recent empirical investigation. This will concentrate on research from the past 20 years (1984-2004) and will consider its relevance and contribution to this area, bearing in mind methodological considerations and limitations. The influence of theoretical descriptions can be persistent even though there is not consistent research support. The review will aim to highlight when theoretical discussions are supported with reliable empirical evidence.

It is suggested that psychologists are the latest descendents of healers and the shaman of primitive and tribal societies. Such individuals have held a special place in society, and are seen to have hidden or mysterious powers. They were expected to be skilled in the art of medicine and to possess special powers enabling them to reach higher levels of awareness or to make contact with the spirit world (Bennet, 1987). The 'cures' obtained from such healers were more reliant on faith and belief than evidence or logic (Guy, 1987). In a similar way, some may consider that modern day healers such as psychological therapists are regarded by society as privileged persons, who we permit access to the hidden aspects of our minds, who use healing 'tools' which are more internal than external.

Historically shamans and healers obtained their position through a psychological journey, involving a symbolic death and rebirth, assimilating a physical or psychological affliction into his or her being (Bennet, 1987). This paradox of one who heals yet remains wounded is at the core of the mystery of healing. The paradigm suggests that deep within each healer lies an inner wound, which may not only play an important role in vocational choice, but constitutes a significant, if not essential factor contributing to healing in the patient (Miller & Baldwin, 1987).

Therapists have an important role in the community, with a certain amount of status attached. It is accepted that for a therapist the more important 'tools of

the trade' are internal rather than external, but how much do we really know about the internal psyche of a therapist, and what is the impact if this is 'damaged'? Personality factors that may motivate people to their career and be helpful to their functioning in that career may, in extreme, be dysfunctional to the psychotherapist and client. In the majority of the literature, the effects of therapists' personal characteristics are evaluated for their influence on clinical practice, rather than for their influence on the total person (Norcross & Prochaska, 1986). This puts the focus of impact on the client rather than the therapist's personal functioning.

In his book, Guy (1987) discusses the satisfactions, or more conscious motivations, for a career as a psychotherapist. These include factors such as independence, intellectual stimulation and recognition as well as personal enrichment and emotional growth. Whilst these seem understandable as motivators and are supported by some studies (Guy, 1987), recent empirical evidence of these factors is not in abundance. As a result the focus of this review is on the internal drives of therapists that may lead them towards this career path.

While Guy (1987) clearly suggests that there are positive and overt satisfactions for the career, he also describes associated drawbacks such as isolation, emotional fatigue, and ethical and legal responsibilities. These are among the many negative aspects of a therapeutic profession that often are

less apparent to those considering such a career than the satisfactory aspects. This may be partly due to psychologists' own self-image; that they must be strong and invulnerable and that to admit such difficulties would be admitting weakness. Another explanation is that the benefits appear to minimise, or even outweigh the negatives. What is not clear is how these explanations may be driven by the internal motivations.

Some individuals are drawn to the career in order to fulfil a desire to help people and improve the quality of life for others. Aiding to relieve human suffering and promoting personal growth makes the therapist feel worthwhile and useful, over and above that associated with many other careers.

Whether this is related to earlier experiences and relationship with parents will be explored later. Whilst these may be valid reasons for choosing the career, their possible contribution to therapist stress and burnout needs to be taken into consideration, along with the relative impact on both the therapist and the client's therapeutic outcome.

1.2 Historical perspective and theoretical background

There is a suggestion in literature and clinical lore, that those interested in a caring profession enter the field either to cure themselves or their parents (Farber, 1985). The early emotional experiences of the future therapist, the characteristics of their parents and the pattern of interactions between the

future psychotherapist and other family members may predispose some towards this field of work, or vocation (Guy, 1987).

The mothers of future therapists have been described as narcissistic and emotionally demanding (Miller, 1987); exhibiting varying degrees of emotional disturbance (Henry, 1966); having a central, controlling role in the family (Ford, 1963); dominantly aggressive or pseudo-feminine and clinging (Guy, 1987). The relationship between future therapists and their mothers has been suggested in literature to be a major factor in determining this career choice. Ford (1963) proposes that the therapist's mother is seen as an understanding, caring, giving person who strives to meet the needs of others. This idealisation has shown to be difficult to change in the therapist, despite possible evidence to the contrary. Ford (1963) reported that many therapists recalled their mother as the 'underdog' against their father. He found that the relationship with mother was more important than with father, and that fathers were described as passive and more emotionally distant. Descriptions of fathers varied from protesting, defensive and bullying, to evident passivity (Ford, 1963). The literature tends to concentrate more on relationship with mother than father, and as is typical of the attachment theory literature, sees the mother as the main and more influential caregiver. The therapist's attachment style may influence his or her approach to therapeutic work and relationships with clients. The therapist's ability to form an alliance may be the most crucial determinant of his or her effectiveness

(Leiper & Casares, 2000), supporting the importance of the relationship between future therapists and their mothers.

Farber (1985) describes a certain family pattern in which mothers turn to their sons to discuss the psychological problems within their marriage. By making confidantes of their sons, the mothers force cognitive and emotional issues upon them that are more suitable for adults (Farber, 1985). Farber (1985) however, makes no similar suggestions in relation to daughters.

Halewood and Tribe (2003) suggest that the child adapts in order to satisfy his or her mother's emotional need. Miller (1987) proposes that narcissistically disturbed mothers may go on to bring up narcissistically disturbed children, continuing the transmission of such disturbances through several generations. In everyday terms narcissism can be used to describe positive feelings about the self, in psychological terms it refers to disorders in individuation and in the formation of the self (Halewood & Tribe, 2003). Miller (1987) suggests that the temperament and early upbringing that leads to narcissism predisposes the individual to seek a career as a psychotherapist.

Glickauf-Hughes and Mehlman (1995) argue that children with narcissistic mothers learn to develop 'emotional antennae' in order to respond to the emotional needs of their parents. They suggest this ability may attract them to therapeutic professions.

It is believed that many future therapists adopt their role early, becoming the 'caretaker' for the family member labelled as the 'patient', and being the 'strong one' in the family (Cushway, 1996). Racusin, Abramowitz and Winter (1981) found that three quarters of the therapists they interviewed were involved as children in caretaking within the family in one form or another, either 'parenting' or 'counselling'. Earley and Cushway (2002) refer to the term 'parentification' describing role reversal situations, when the child is assigned an adult role and responsibilities which the parents have abdicated. In trying to resolve unmet needs from their own childhoods, parents seek practical and emotional care from their children, resulting in a family dynamic where children become invisible, learning that their own needs are less important than other's (DiCaccavo, 2002). Unable to provoke a caring response from the parent, the child becomes skilled at anticipating the needs of others as their principal way of relating to the parent. As an adult, this strategy for relating is further established where parentified individuals enter helping professions, taking on careers that represent extensions of their childhood roles (DiCaccavo, 2002).

The literature contains many references to the 'wounded healer' concept, where the decision to enter caring professions is predisposed by the desire to rework the hurts and disappointments of early life (e.g. Bennet, 1987; Miller & Baldwin, 1987, Sussman, 1992). By caring for the patient or client, parentified individuals can care for themselves at a distance, exposing

themselves to emotional distress that may in fact mirror their own, while at the same time defending against direct personal recognition of losses (DiCaccavo, 2002). Choosing such a career may form a means of gaining the validation and recognition for caring for others that an individual does not get from their family.

The Wounded Healer model proposes an interaction between the conscious and unconscious aspects of both the professional (for example doctor or psychologist) and the patient. The theory suggests that the therapist's conscious is interacting with the patient's conscious, and at the same time stimulating interaction with the patient's unconscious, arousing their own healing potential, in this particular context. At the same time, the therapist's unconscious or 'potential patient within' is engaging with the patient's conscious and unconscious, implicitly acknowledging their own wounds or weaknesses, thereby facilitating healing in the patient. The 'wound' referred to may consist of physical or psychological afflictions, and the assumption is that all wounds affect an individual's self-concept, increasing their sensitivity or vulnerability (Bennet, 1987). The proposal is that this wound is sustained whilst a child, when the individual's self-concept is being developed.

Bennet (1987) suggests that a specific consequence of early emotional deprivation may be a powerful drive to care. Guy (1987) states that many therapists have reported that they entered the profession in order to fulfil

some of their deeper needs for closeness and intimacy due to a sense of isolation prevalent during their childhood. He proposes that this may have resulted from early traumatic events related to their family life (Guy, 1987). Several authors describe therapists and health professionals as having backgrounds that lead them to experience “a special sense of isolation”, or incidents that made them feel “different” (e.g. Farber, 1985; Henry, 1966). Storr (1990) suggests that those attracted to psychotherapeutic professions have personal knowledge of experiencing insult or injury which results in extending their capacity for compassion. Menninger (1957) argues that therapists tend to have experienced some form of rejection from one or both parents, suggesting this as an explanation for their interest in the emotionally vulnerable.

Many who choose to become a therapist seem to possess a natural tendency to be introspective; this has been termed psychological mindedness. This is an individual's interest in and ability to reflect on motives, psychological processes and inner experiences of both the self, and the self's relationship to others (Trudeau & Reich, 1995). Whilst this appears to be inherent in individuals pursuing this career, it is reinforced by the nature of training and increases with age and experience in the profession (Farber, 1985). Whilst in the literature the inner wound and psychological mindedness are discussed as separate concepts, they appear to be

intricately related. It may be that psychological mindedness is a more overt, or conscious display of the inner wound.

1.3 A description of the empirical evidence

There has only been a limited number of studies that have directly examined unconscious motivations of choosing a caring career and the implications of such factors. The research which has been identified has attempted to consider the impact of family factors such as relationship with parents and family illness. It has also examined the identification of personality characteristics that psychological therapists have in comparison to other professionals, and the impact of these on therapeutic outcome. Of the literature on therapist stress and burnout, there is a lack of studies focusing on and exploring internal factors rather than external influences such as responsibilities and resources.

1.4 Early experiences

Some studies have looked to the family of origin to answer questions of motivations. The studies discussed here, with the exception of one, are questionnaire based and all required retrospective self-report. The focus of these studies has been the frequency of trauma, family dysfunction and physical or psychiatric illness within the immediate family during childhood. Whilst the relation of these factors to the wounded healer paradigm is not

explicit in most of these studies, the relevance of childhood for the internalisation of a physical or psychological wound should be considered.

Wolgien and Coady (1997) interviewed therapists regarding the development of their helping ability. They concluded that it was the therapists' problems with difficult personal issues and experiences, both as a child and adult, that allowed them to be sensitive to, and supportive of, the clients' difficulties and to develop respectful, meaningful relationships with them. They suggest that these struggles with difficult issues and experiences support the proposal of the wounded healer paradigm as being appropriate to therapeutic professions and associated with therapeutic effectiveness. It is interesting that their sample consisted solely of 'good' therapists who had been identified by knowledgeable colleagues as particularly effective therapists, based on descriptions from literature. This distinction is quite subjective and questionable, and leads to queries as to whether the development of helping ability in 'poor' therapists is influenced by the same or different factors.

Of the studies attempting to examine the prevalence of relevant early experiences, there is a range in the selection of an appropriate comparison group from arts students (DiCaccavo, 2002) and non-psychiatric doctors (Frank & Paris, 1987; Krenek & Zalewski, 1993); to physicists (Fussell & Bonney, 1990) and a variety of occupations or the general population (Elliott & Guy, 1993; Leiper & Casares, 2000). The results suggest that whilst

therapists report higher levels of family dysfunction or problematic childhoods (Elliott & Guy, 1993; Fussell & Bonney, 1990) their level of psychological distress is significantly less (Elliott & Guy, 1993). The implication of this could be that the therapists have used the knowledge and experience gained during their career to reduce the impact of their past and the level of psychological distress they experience. This relates to hypotheses discussed by Farber (1985) that psychological therapists choose their careers to heal themselves or to heal their families which have been investigated by Frank and Paris (1987). Their study, using psychiatrists, did suggest some support for the first hypothesis, regarding healing the self, finding that psychiatrists rate themselves as being significantly more disappointed in their mothers and fathers. Fathers were seen as less admirable and less calm, mothers as less admirable and less consistent.

Frank and Paris (1987) did not find support for Farber's view that psychiatrists are motivated to heal their parents. This conclusion is based on their comparison group of non-psychiatrist doctors. Krenek and Zalewski (1993) failed to find significant differences between the prevalence of family psychopathology between mental health professionals (psychologists and psychiatrists) and family doctors. It could be argued that the unconscious motivations and influence of early life on entering any caring profession are similar. Therefore medical doctors may be inappropriate as a comparison

group for mental health professionals, making the conclusions of such studies difficult to usefully interpret.

In their studies both Krenek and Zalewski (1993) and Wolgien and Coady (1997) found that the presence of a psychiatrically ill relative or family problems was influential for their participants in career choice. Krenek and Zalewski (1993) also found that feelings of guilt and anger towards the ill family member impacted on their self-perceived therapeutic effectiveness. In a similar vein, DiCaccavo (2002) argued that the experience of parentification as a child motivated people towards a career in counselling psychology.

Interestingly, DiCaccavo (2002) describes gender differences influencing the route into parentification, and later career choice. She suggests that under-responsibility is relevant for men. By being more cared for by their mothers, men run the risk of feeling guilt and obligation, keeping them enmeshed in family systems. The result may be seeking to find an outlet for their need to care by becoming professional helpers. In contrast, DiCaccavo (2002) proposes that for women, parental neglect and accepting care-taking roles for family members leads to ideas about themselves being good at caring and being responsive to the needs of others. Eardle, Sansom, Cole and Heapy (1992) looked at gender differences in types of helping behaviour displayed by undergraduate psychology students. Their results suggested

that women scored higher for low-risk, low physical strength helping behaviours, and lower than men for high-risk, high physical strength behaviours. The focus of Leiper and Casares' (2000) study was on the attachment organisation of clinical psychologists. They suggest that the majority of clinical psychologists fall within the 'compulsive care-giving' pattern of attachment, which would fit with DiCaccavo's (2002) study for both men and women, suggesting that the need to care is the end result, whichever route is taken.

1.5 Personality factors and impact on effectiveness

As discussed earlier, Miller (1987) highlights the role of narcissism in both future therapists and their mothers. This hypothesis was directly investigated by Clark (1991). Her study, using the Narcissistic Personality Inventory, compared Master's level students studying counselling psychology, business and educational computing in the United States of America (USA). The results did not find that counselling psychology students scored significantly higher. Recently Halewood and Tribe (2003) measured narcissistic injury in trainee counselling psychologists. Narcissistic injury refers to a specific type of psychological damage which focuses on feelings about the self and past relationships related to self-development (Miller, 1987). The results found that counselling psychology students scored significantly higher than mature postgraduate students on a measure devised from Miller's (1987) ideas.

Whilst the results of these studies appear to be contradictory, the applicability of the measures needs to be considered. The Narcissistic Personality Inventory was designed to measure pathological narcissistic traits. The use of psychological language and concepts in the injury scale was affected by the control group's understanding, and therefore the accuracy of their scores. Measuring self-reported narcissism is a curious concept. By its nature, a respondent who has completely shut off his or her narcissism will deny it completely. More generally, defensiveness and a desire to present well, which are both narcissistic traits, would impact on self-response.

The idea of being able to reflect on the inner experiences of the self is inherent to the concept of psychological mindedness. Trudeau and Reich (1995) found that psychology students were significantly more psychologically minded than other social science students. Whilst it can be argued that psychological mindedness may increase with knowledge of and experience in psychology, the participants were undergraduates rather than students carrying out further study in the area of clinical psychology. Trudeau and Reich (1995) also found a correlation between psychological mindedness and well being. Norcross and Prochaska (1986) looked at psychological distress and coping. Whilst psychologists reported significant periods of psychological distress during the previous three years, they were more likely to use interpersonal coping strategies in comparison to lay-

persons who relied more on internal processes, such as self re-evaluation and wishful thinking.

Three recent studies have explored psychological adaptation in trainee clinical psychologists (Brooks, Holtum & Lavender 2002; Kuyken, Peters, Power & Lavender 2003; Kuyken, Peters, Power, Lavender & Rabe-Hesketh 2000). Lazarus and Folkman (1984) suggest there are three dimensions to the concept of psychological adaptation: morale, social functioning, and somatic health. Kuyken et al. (2000) found that initially the psychological adaptation of the trainees in their sample fell within the normal range for employed adults. However, over the duration of the three year training the trainees reported significant increases in work adjustment problems, depression and interpersonal conflict. This agrees with Brooks et al., (2002); who found that trainee clinical psychologists had a significant problem with anxiety, depression or work adjustment. In a more recent study Kuyken et al. (2003) found that trainees who didn't experience such difficulties appraised the demands of the course as manageable, reported greater access to appropriate support and reported fewer problems with psychological adaptation. This suggests that personality factors may influence adaptation.

The implications of these studies suggest greater awareness of the potential negative impact of training on individuals. The studies suggest an ongoing review of trainees' personal, social and professional adaptation as it relates

to learning and work. Kuyken et al. (2003) found that trainee problems tend to increase during training and tend to be of the internalising type. As stated previously, Norcross and Prochaska (1986) found that the psychologists in their sample did not rely on internal coping strategies, and concluded that they were older and more educated than the comparison sample. This raises the hope that once qualified, psychologists become more adept at using the coping strategies they learn through their work and with increased experience.

Other studies have concentrated on the functioning of qualified therapists. Guy, Poelstra and Stark (1989) found that of psychologists who reported experiencing personal distress during the previous three years, one third reported that this decreased the quality of care their patients received. Again by the nature of self report studies, it is not clear from those who did not report decreased quality of care whether this was due to denying the impact or to successful prevention of the effect of their distress. Dunkle and Friedlander (1996) found that the therapist's level of self-directed hostility, perceived social support and degree of closeness in interpersonal relationships were significantly predictive of the bond component of the working alliance with clients. These results agree with those of Henry, Schacht and Strupp (1990) who found that the therapists of patients showing no introject change engaged in hostile, blaming, ignoring and separating sequences in therapy. They looked at patient and therapist introject and

psychotherapy outcome. The principle of introject theory is that people learn to treat themselves as they have been treated by others, which relates back to the impact of family of origin. However, Beutler, Machando and Neufeldt (1994) discussed studies that failed to replicate these findings.

In the process of considering whether therapists' psychological makeup is significantly different to that of other professions, it is worth mentioning the comparison of practicing therapists to scientific, research oriented psychologists. Conway (1988), Tinsley, Tinsley, Boone and Shim-Li (1993) and Youniss, Lorr and Stefic (1985) both found that scientists and practitioners varied on a range of personality characteristics. Their results suggest that more scientific or academic psychologists were more theoretical and achievement oriented, whilst practitioners are more altruistic, person-oriented and materialistic.

1.6 Stress and burnout

There is a variety of literature considering stress and burnout in psychological therapists. The majority of this discusses the influence of external factors such as the demands of training (e.g. Cushway, 1992); patient behaviour (e.g. Hellman, Morrison & Abramowitz, 1987a); organisational issues (e.g. Millon, Millon & Antoni, 1986), or that burnout may be amplified by difficulties in acknowledging distress (e.g. Cushway, 1995). Two studies explored the role of specific personal factors in levels of

stress. Hellman, Morrison and Abramowitz (1987b) suggest that a degree of personal flexibility and incorporating some professional distance may minimise stress from problematic patient behaviours, such as suicide threats. Mills and Huebner (1988) found that extraversion was related to emotional exhaustion and agreeableness to depersonalisation in school psychologists. Both studies suggest that the personal factors were more predictive of stress levels than patient or environmental factors.

1.7 Summary of empirical studies

These studies suggest that some psychological therapists report family dysfunction, illness or difficult personal experiences. It is not possible to convincingly conclude whether this is significantly higher than in the general population, and therefore predictive of career choice. It could be suggested that studies focusing on the impact of such experiences, rather than the prevalence in early life, would be of more value. The literature does suggest that whatever the origin of stress or distress, personal factors influence the impact on therapeutic outcome for the clients as well as on the therapists' coping strategies and adjustment. Training appears to exert a large amount of stress on developing therapists which has a negative impact on work adjustment and emotional well being.

1.8 Methodological and conceptual considerations

The focus of this review has been the influence of early childhood experiences and personality, which could affect psychological therapists' choice of a caring profession. Although some studies focused on specific concepts, such as the wounded healer and narcissism, a large number of studies have explored different personal factors. This limits the comparisons to be made across studies and ultimately the conclusions that can be drawn from the literature.

A notable limitation to the literature is the reliance on self-report methodologies. Self-report of personality characteristics is subjective and dependent on self-awareness, besides the influence of mood, situation and current functioning. This applies to both the identified population and the comparison groups used. The essence of most childhood experience studies is that the data collected are retrospective. The results therefore, are subject to forgetting, selective recall and bias from subsequent experiences and interpretation. In addition to subjective report and selective recall is the potentially confounding factor of subsequent psychological knowledge and personal development. By the nature of their profession and training psychological therapists increase their awareness of the impact of family dynamics and the influence of personal factors on psychopathology. These aspects would naturally influence their responses on the measures used. As alluded to in this review, there is a typical image and expectation of

therapists as being emotionally balanced and adjusted which may affect self-report.

Other factors of consideration with this area of research include the selection of samples and comparison groups. Often the samples are self-selected which may bias the results; for example the study may be more attractive to a subsection of the wider population or particular therapists, thereby influencing who chooses to participate. It is worth considering why people may not have chosen to participate as well as considering those who have. The studies often suffer from small sample sizes and a range of comparison groups. The suitability of some groups is questionable, for example family doctors. Also questionable are the assumptions leading to their selection by having very different characteristics to psychological therapists, such as physicists. Add to this the array of measures used, not necessarily standardised for the sample population, and overall interpretation and conclusions from the data become more difficult.

As indicated by this review, concepts such as the wounded healer are extremely difficult to test empirically, yet the phenomenon has persisted. In that respect a comparison could be drawn with Freud's theories; whilst they are difficult to test it does not mean that they are not useful as explanatory concepts. The theories have persisted over time and have been observed informally as present in psychological therapists and others, contributing to

the endurance of the concept. While it may not be possible to prove the existence of such concepts, it may be helpful to hold them in mind because of their implications for therapeutic work.

1.9 Clinical implications

The literature does suggest that people may use their personal experiences in their therapeutic work which may help increase empathy. However, the impact of therapists using themselves as a therapeutic tool on both the therapists and clients needs to be carefully monitored. It is important to acknowledge that personality and life experience factors will have a consequence for their performance and levels of stress. As a result a range of support options should be available to suit the individual, particularly at times of distress in therapists' personal lives and during training. The research does not suggest the need for extensive exploration in the history of potential candidates for the presence of family dysfunction or early care-taking roles. Although something that would certainly be helpful during the selection process could be consideration of the individual's responses to stress and adjustment experiences during their life and career to date.

The use of support systems, such as peer supervision or a therapy network should be considered and available at all stages of the career. Whilst the literature does suggest therapists use interpersonal coping strategies, the

impact of self-directed negativity or hostility clearly had an unhelpful effect on therapeutic alliance or outcome.

It is interesting that research has attempted to define the absolute characteristics of the caring professions when the reality is that we are all governed, to some extent by our experiences, and that a feature of therapy is that individuals respond in different ways to similar situations. Whilst concepts such as wounded healer can be observed in therapists, they are also present in some people who do not follow therapeutic professions. It is likely that people who have predisposing personalities do have a choice. Some people make a healthy, conscious choice not to pursue a caring profession, whilst others make the choice to follow such a career, but protect themselves. People have a choice how they heal their wound, however self-awareness is important. The inner wound can make people good, empathic therapists, as long as they protect themselves. It is those who do not have the awareness to ensure they protect themselves who may experience greater difficulty in their private or professional lives.

1.10 Future directions for research

Whilst studies have looked at the impact of stress during training and when qualified, it may be interesting to look at the long-term effect, from trainees throughout their career progression, seeing whether it is the same people who experience more difficulty, and considering the impact of increased

knowledge and experience. The studies clearly suffer from lack of appropriate measures. One of the problems is the indefinable nature of some of the constructs being explored. Ultimately, it could be concluded that rather than focusing on the histories of the psychological therapists, the real importance is on the increased exploration of the impact on the person, and subsequently their therapeutic effectiveness. The field of research could benefit from attention to those aspects that can be studied to assist therapists in the present.

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Positive change and coping in carers of people with acquired brain injury

Abstract

This study explores the self-report of positive change as a result of becoming a carer for a family member with acquired brain injury (ABI). Relationships between positive and negative changes, coping strategies and mental health symptoms were examined. Participants were 36 carers, both male and female, recruited through charities supporting carers and people with ABI. Positive and negative changes were measured using the Post-Traumatic Growth Inventory and the Changes in Outlook Questionnaire. The Brief COPE was used to measure coping strategies and the 12-item version of the General Health Questionnaire measured mental health symptoms. Results indicated that a substantial number of carers report at least one positive change since becoming a carer. Negative change was more predictive of mental health symptoms, decreased satisfaction with coping and use of maladaptive coping strategies. This suggests the value of interventions aimed at reducing negative effects and increasing satisfaction with coping.

2.1 Introduction

Caring for a family member with an acquired brain injury (ABI) can be stressful and result in feelings of strain, burden and depression (e.g. Blake, Lincoln & Clark, 2003; Oddy, Humphrey & Uttley, 1978; Sandler, High, Hannay & Sherer, 1997). Whilst most research over the last few years has concentrated on these negative outcomes, there is some evidence for positive aspects of caring, and that these may contribute to a reduction in negative consequences (e.g. Cohen, Colantonio & Vernich, 2002). This study will explore whether there is a relationship between positive changes and carer's mental health, and the impact on their coping abilities.

People who suffer from an ABI resulting from a stroke, haemorrhage or head injury often return home to live with partners and family. It often then falls to these people to become their informal carers. Family members may be caring for a person very different to the one they knew before the injury, showing a range of emotional, behavioural and cognitive problems (Knight, Devereux & Godfrey, 1998). It often appears that the psychological changes rather than physical impairments have the greatest impact on informal carers (Bowen, Tennant, Neumann & Chamberlain, 2001; Marsh, Kersel, Hewill & Sleight, 1998) and contribute to increased incidence of family breakdown (Bowen et al., 2001). It has been suggested that the strain carers experience may increase over time, from first year to fifth year post injury, (Brooks, Campsie, Symington, Beattie & McKinlay, 1986). Responses to stressful

events vary from individual to individual on a number of factors (Degeneffe, 2001) and result in a range of symptoms including anxiety (Marsh et al., 1998), depression (Harris, Godfrey, Partridge & Knight, 2001) and decreased quality of life (Moules and Chandler, 1999).

In addition, there is a growing body of literature demonstrating that people report growth and positive life changes following traumatic events (Tedeschi, Park & Calhoun, 1998). The areas in which individuals report post-traumatic growth (PTG) tend to reflect three general life domains: changes to one's perception of self; changes in relationships; and changes in spirituality or life philosophy (Frazier, Conlon & Glaser, 2001). The PTG model suggests that positive changes generally increase over time and negative changes generally decrease over time (Tedeschi & Calhoun, 1995).

In order to gain a balanced picture of life following trauma, it is necessary to consider both the positive and negative changes that result from the acquisition of the informal carer role. Frazier and colleagues (2001) report that studies looking at both positive and negative changes found negative changes to be more strongly related to distress than positive changes. When considering a balance between positive and negative, it is important to acknowledge that a series of factors may first influence whether or not growth occurs, and secondly influence the extent of the growth. These include personality, context and prior life experience (Tedeschi et al., 1998).

In their study identifying positive aspects of caring for a person with dementia, Cohen et al. (2002) found that over 70% of their sample could identify at least one positive aspect of caring. Orbell, Hopkins and Gillies (1993) obtained evidence for both positive and negative care-giving appraisal constructs, whilst Knight et al. (1998) found that many of the negative comments expressed in regard to caring for a relative with ABI were balanced by positive accounts.

As suggested, people vary in their response to becoming a carer for someone with ABI (Man, 2002) and can have a range of positive and negative outcomes (Orbell et al., 1993). Some relatives show few signs of stress caring for very difficult patients, whilst some seem to be under extreme strain with relatively less damaged patients (Mitchey, Gray and Pentland, 1996). Individual reactions to stressful events vary according to their personal appraisal of the stressful event and the extent of coping strategies they employ (Degeneffe, 2001; Mitchey et al., 1996). Coping strategies refer to cognitive and behavioural efforts to manage or reduce stressful conditions and the associated emotional distress (Lazarus and Folkman, 1984). Strategies vary and have been classified in terms of a problem- (what people do) and emotion- (changing their appraisal) focused approach (Lazarus, 1991).

Various authors have suggested alternative theories for the impact of coping on stress and strain experienced by carers. Mitchey et al. (1996) suggest that reducing maladaptive coping responses is the key to reducing stress, whereas Knight et al. (1998) believe it is the carer's ratings of their satisfaction with their ability to cope that predicts burden, and that lack of satisfaction with the caring role may be a 'risk' indicator (Cohen et al., 2002). Degeneffe (2001) highlights the importance of pre-injury family characteristics and Harris et al. (2001) point to the role of effective social support. Lazarus and Folkman's (1984) interaction model of stress appears to combine these ideas by proposing that appraisals of stress, external social support, and coping responses are significant mediators in the experience of stress.

Positive gain and growth following trauma is a relatively new area. There is limited literature on positive aspects of caring and no published studies were identified looking specifically at PTG and carers of people with acquired brain injury. In addition the relationship between growth (if present), coping and the outcome for an individual has not been well explored. The available literature suggests that positive changes increase as negative changes decrease, and also indicates the role of coping responses in mediating stress reactions, and ultimately mental health. The aim of this study is to explore whether carers report positive changes. It is hoped to establish whether growth and positive changes as a result of caring are associated

with reported use of coping strategies and can help protect against negative consequences, specifically mental health symptoms.

2.2 Method

2.2.1 Design

The study involved a postal questionnaire survey. The sample was self-selected in that questionnaire packs were distributed and participation was optional.

2.2.2 Ethical approval

Ethical approval for this study was awarded by Coventry University Research Ethics Committee in June 2003; Warwickshire Research Ethics Committee in July 2003; Coventry Local Research Ethics Committee in October 2003 and Hereford and Worcester Local Research Ethics Committee in November 2003 (see Appendix A).

2.2.3 Participants

Participants were approached through local charities offering advice and support to carers and people with ABI, their family and carers. Carers were defined as a person who spends a significant amount of time with or lives with, a person with acquired brain injury. Of 225 questionnaire packs that were distributed to carers 36 were returned completed, a return rate of 16%. All participants were at least 6 months post injury; the mean was 82.76

months (6 years, 10 months) and were mainly strokes (58.3%), haemorrhages (5.6%) or traumatic brain injury (5.6%). The respondents were mainly female (86.1%) and overall consisted of spouses (52.8%), parents (25%, including 1 step-mother), and adult children (13.8% including 1 daughter-in-law) who provided a range of support for the person with ABI and received a variety of support from friends, charities, care agencies, etc. Wives constituted 44.4% of the sample.

2.2.4 Measures

See Appendix B for copies of measures.

Brief COPE (Carver, 1997)

This is a multidimensional coping inventory used to assess the different ways in which people respond to stress. There are 28 items rated from 0 (I haven't been doing this a lot) to 3 (I've been doing this a lot). It consists of 14 scales (active coping, planning, positive reframing, acceptance, humour, religion, use of emotional support, use of instrumental support, self distraction, denial, venting, substance use, behavioural disengagement and self-blame). This gives an overview of how people rate their coping abilities and the strategies they find most helpful. The scale has adequate internal reliability (Carver, 1997). The brief version was selected in preference to the original full COPE to reduce participant fatigue. The scale was modified by the addition of another variable, as suggested by Knight et al. (1998) relating

to carers' satisfaction with their ability to cope to see whether this is related to report of mental health symptoms.

Changes in Outlook Questionnaire (CiOQ)

(Joseph, Williams & Yule, 1997)

This is a 26-item self-report measure designed to look at positive (11) and negative (15) changes following trauma. Items are rated on a scale from 1 (strongly disagree) to 6 (strongly agree). This measure has high content validity and good internal reliability (Joseph et al., 1997).

Post-traumatic Growth Inventory (PTGI) (Calhoun & Tedeschi, 1999)

This inventory is used to determine where a client is in the process of growth reflecting 5 domains: appreciation of life; new possibilities; spiritual change; relating to others; and personal strength. The inventory consists of 13 items; each rated on a 6-point scale from 0 (I did not experience this change) to 5 (I experienced this change to a very great degree). The Inventory appears to have adequate internal reliability and test-retest reliability (Cohen, Hettler & Pane, 1998).

General Health Questionnaire (GHQ-12) (Goldberg 1978)

This is a self-administered screening questionnaire for detecting psychiatric disorder. It is being used to gain an estimate of the effects of caring on the

carer's mental health. The 12-item version was used and was scored in two ways.

Firstly, responses were awarded a rank score from 0-3. This provided data with which higher levels of psychiatric symptoms could be compared statistically with higher levels for other measures. Secondly, the GHQ-12 scoring system of awarding 0-0-1-1 to the responses was used. This provides details of the number of participants who fall above a cut-off point, indicating caseness for psychiatric symptoms. The GHQ-12 has been found to have good reliability and validity (Goldberg, 1978).

Demographic Information

In addition, information was collected relating to the nature of the brain injury; information regarding the relationship between the carer and person with brain injury; support provided by the carer; as well as information relating to age, gender, etc.

2.2.5 Procedure

Study packs were compiled containing a study information sheet, consent form, the questionnaires (see Appendices B, C & D for details) and a pre-paid envelope for their return. To maintain confidentiality, the packs were given to the participating organisations to distribute to the carers they considered to fit the definition. In addition a carer support group was attended to discuss the study and recruit participants. Once questionnaires

were returned completed, consent forms were stored independently of questionnaires to ensure confidentiality.

2.2.6 Analysis

Descriptive statistics were used to identify trends in the returned questionnaires and correlations were conducted to explore whether post-traumatic growth is related to coping strategies or mental health symptoms. All statistical calculations were carried out on the Statistical Package for the Social Sciences (SPSS) computer package, version 11.

2.3 Results

Whilst the majority of people being cared for were male, the majority of the carers were female. Wives and mothers constituted a substantial proportion of the sample. The care they were providing was often a combination, including help with daily activities and emotional support. See Appendix E for a fuller picture of the participants' circumstances.

Table 2.1 provides a summary of scores on the questionnaire measures.

Using the GHQ-12 to measure caseness for psychiatric symptoms, 18 participants (50%) scored at or above a cut-off score of 3. Overall the participants rated positive changes higher than negative changes.

Satisfaction with ability to cope was rated on a five-point scale. The mean of 2.85 suggests that more participants were satisfied with their ability to cope

than were not satisfied. The coping strategies of active coping and acceptance were rated as used more often than the other coping strategies. Denial and behavioural disengagement were rated as used least often.

For the CiOQ, frequencies were calculated by adding the number of people who rated themselves as agreeing with the item (a score of 4 or more). Over half the participants agreed with each of the positive change items (from 55.5% to 86.2%). These changes are shown in Tables 2.2 and 2.3. The changes agreed with most frequently were “I value other people more now”, “I feel more experienced about life now” and “I value my relationships much more now”. These were agreed with by over 80% of participants.

Table 2.1 Means, standard deviations (S D) and range for questionnaire totals and scale scores

Questionnaire	Mean	S D	Range of participant scores
COPE			
- Acceptance	5.36	1.13	0-6
- Active Coping	4.14	1.78	0-6
- Planning	3.83	2.24	0-6
- Emotional Support	3.26	1.82	0-6
- Instrumental Support	3.14	1.64	0-6
- Positive Reframe	3.03	1.86	0-6
- Self-distraction	2.12	1.55	0-5
- Venting	1.71	1.58	0-6
- Religion	1.71	1.87	0-6
- Humour	1.50	1.98	0-6
- Self Blame	1.17	1.36	0-6
- Substance Use	0.78	1.33	0-4
- Behavioural	0.75	1.29	0-5
Disengagement			
- Denial	0.50	1.03	0-3
Satisfaction with Coping	2.85	0.82	0-4
PTGI Total	32.20	11.46	9-58
CiOQ			
- Total Positive Changes	46.62	8.72	17-62
- Total Negative Changes	36.28	16.44	19-79
GHQ-12 Total (scale of 0-3)	14.19	6.17	2-29

Table 2.2 Frequency and percentage agreement with positive change items on Changes in Outlook Questionnaire (CiOQ)

Item	Frequency	Percentage
<i>Positive Changes</i>		
value other people more now	31	86.2
feel more experienced	30	83.4
value relationships more	29	80.5
look upon each day as bonus	28	77.8
more understanding & tolerant	28	77.8
don't take life for granted	26	72.2
no longer take people/things for granted	27	74.9
live everyday to the full	25	69.4
don't worry about death	21	58.3
greater faith in human nature	20	55.6
more determined to succeed	20	55.6

Agreement signified by score of 4 or more on 6-point likert scale

Less than 50% of the participants agreed with any one negative change on the CiOQ. The most frequently agreed with statements (over 40%) were “I feel very much as if I’m in limbo” and “I desperately wish I could turn back the clock to before it happened”. The least reported changes were “My life has no meaning any more” and “Nothing makes me happy any more”. Less than 10% of participants agreed with these statements.

Table 2.3 Frequency and percentage agreement with negative change items on Changes in Outlook Questionnaire (CiOQ)

Item	Frequency	Percentage
<i>Negative Changes</i>		
feel very much in limbo	16	44.4
wish could turn back clock to before	15	41.7
very little trust in others	12	33.4
don't look forward to future	11	30.6
something bad waiting around corner	11	30.6
feel harder towards others	11	30.6
fear death very much	10	27.8
sometimes think not worth being good person	9	25
less tolerant of others	9	25.1
no longer feel able to cope	5	13.8
very little trust in myself	5	13.8
feel dead from neck down	5	13.8
much less able to communicate	4	11.1
life has no meaning	3	8.4
nothing makes me happy any more	2	5.6

Agreement signified by score of 4 or more on 6-point likert scale

Individual Spearman's rho correlations were conducted for the total scores of positive and negative changes on the Changes in Outlook Questionnaire and total of Post-traumatic Growth Inventory (dependent variables), with the scales of COPE, satisfaction with coping and total GHQ-12 score (independent variables). See Tables 2.4 and 2.5 for correlation coefficients. Correlations were also computed with participant age and time since injury to check for confounding relationships with variables.

Table 2.4 Correlation coefficients for independent variables

	Participant	Time Since	PTGI Total	CiOQ	CiOQ
	Age	Injury		Positive	Negative
Participant Age		.17	-.21	.07	.01
Time Since	.17		.05	.12	.07
Injury					
Active Coping	.03	-.09	.17	.12	.08
Planning	-.19	-.05	.26	.06	.08
Positive	-.33	.02	.43*	.40*	-.15
Reframe					
Acceptance	-.01	.09	-.15	-.29	-.38*
Humour	-.13	-.12	.08	-.23	-.32
Religion	.30	.19	.14	.36	.04
Emotional	-.42**	-.13	.38*	-.00	-.15
Support					
Instrumental	-.16	-.24	.44**	-.10	-.18
Support					
Self-distraction	.11	.04	.05	.02	.39*
Denial	-.04	.08	.42*	.39*	.53**
Venting	-.25	-.11	.23	.07	.42*
Substance Use	-.27	-.13	-.29	-.22	.14
Behavioural	-.26	-.07	.03	.09	.41*
Disengagement					
Self-blame	.04	.14	.16	.10	.49**
Satisfaction	.12	.05	-.08	.07	-.39*
GHQ-12 Total	.07	-.02	.10	.10	.60**

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Table 2.5 Correlation coefficients for dependent variables

	Participant Age	Time Since Injury	PTGI Total	CiOQ Positive	CiOQ Negative
PTGI Total	-.21	.05		.62**	.19
CiOQ Positive	.07	.12	.62**		.29
CiOQ Negative	.01	.07	.19	.29	.

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Age was negatively correlated with use of emotional support as a coping strategy. Total PTGI and CiOQ positive changes were highly correlated. They were both associated with the COPE scales positive reframing and denial. In addition, PTGI total was associated with higher scores for use of both emotional and instrumental support. Total negative changes on CiOQ were associated with higher scores for self-blame, denial, venting, self-distraction, behavioural disengagement and total GHQ-12. Total negative changes on CiOQ were associated with lower scores for satisfaction with coping. Total negative changes were also negatively correlated with acceptance.

2.4 Discussion

The results show that a substantial number of carers report experiencing positive changes as a result of becoming a carer. Participants reporting

higher agreement with negative changes rate themselves as experiencing poorer mental health. Negative change was found to be related to more maladaptive coping strategies such as self-blame and denial and negatively associated with satisfaction with coping. This suggests that negative changes and maladaptive coping strategies may be more predictive of poor mental health than positive changes. The results are consistent with other research suggesting that carers report positive expressions related to caring (Cohen et al., 2002; Knight et al., 1998) and that negative change is more predictive of mental health status than positive changes (Frazier et al., 2001).

This study is limited by the low response rate (16%). There are several potential explanations for this result. It is conceivable that the carer may perceive themselves as struggling to cope and therefore would have found it difficult to face completing the questionnaires, or felt they didn't have the time to do so. If that is the case then the sample presented may be biased towards those who rate themselves as coping more successfully. Another factor to consider in response rate is the organisations who offered to help distribute questionnaire packs. In some instances, none of the numbered packs provided to certain charities were returned. This may be a coincidence, it may reflect a lack of explanation or clarity from the lead author, or competing priorities may have resulted in the packs being set aside and forgotten. Whilst efforts were made to follow up these

questionnaire packs, this did stop short of harassment. The small sample size made comparisons between different relationships to the person being cared for and time periods of caring impossible in this study.

When considering these results, thought should be given to the appropriateness of the measures used. The measures for post-traumatic growth and changes were designed for use with populations following trauma. Whilst it is a valid argument that the participants in this study have faced trauma, the trauma may be qualitatively different to experiencing a life-threatening situation directly. The result may be reduced sensitivity of the measures to changes experienced. Another possibility is that the rumination processes following the ABI may result in re-evaluations and changes of differing types for the person who sustained the ABI and their main carer. Cohen et al. (1998) suggest that researchers should be cautious of the accuracy of self-reported positive outcomes, that they could be influenced by denial or unrealistic positive evaluations or optimism about the future. This suggests the use of behavioural indicators in addition to self-report of growth.

If the sample does reflect carers who perceive themselves as coping better, a consequence may be that the people coping less well may not be as proactive in seeking help and support. The result of this could be a hidden population of carers without the necessary coping strategies to manage their

situation. An implication for professionals is to be actively aware that carers may require support even if they are not forthcoming in seeking it or recognise their own need.

The relationship between negative changes and poorer mental health suggests a role for professionals in addressing these negative changes following the uptake of a caring role in an attempt to avoid poor mental health in carers. Mant, Carter, Wade and Winner (2000) suggest the role of family support in improving quality of life for carers. These results also point towards the involvement of professionals in reducing the maladaptive coping strategies employed by carers, given their greater association with negative changes. Mitchey et al. (1996) suggest that it is maladaptive strategies which should be addressed, as negative responses increase stress. A focus on positive changes to increase satisfaction with coping may help reduce negative changes and improve mental health symptoms.

Future research may be helpful to look in more detail at the positive changes experienced in carers and their potential to mediate coping responses and carer well-being. Whilst this study attempted to address these issues, the development of measures more suitable for this population would be beneficial. Given the limitations of self-reported growth, future research would be helpful using behavioural indicators of positive change, such as increased altruism or greater problem solving skills, in addition to self-report

measures. A disadvantage of quantitative research is the potential loss of information related to individual circumstances which may be influential. A few participants provided extra information regarding their individual context, potentially because they felt the questionnaires did not fully reflect their circumstances.

In conclusion, carers of people with acquired brain injury in this study identified at least one positive change they experience as a result of becoming an informal carer. Negative changes as a result of being a carer led to reduced satisfaction with ability to care, increased maladaptive coping responses and poorer mental health. This suggests a role for professionals in reducing negative changes and increasing satisfaction with coping. Future research directions would benefit from the use of behavioural indicators to complement self-reported growth.

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Positive change and the experience of being a wife of someone with acquired brain injury

Abstract

The aim of this study is to explore the use of post-traumatic growth (PTG) as a framework to understand the experience of being a wife of someone with acquired brain injury (ABI). Participants were six wives who were identified through contact with charities supporting carers and people with acquired brain injury. Semi-structured-interviews were conducted regarding how wives felt their lives had changed and included the life domains where growth has been reported (perception of self, interpersonal relationships and philosophy of life). Thematic analysis using Interpretative Phenomenological Analysis (IPA) was applied to analyse the data. The results show that the wives interviewed drew on previous strategies and experience to assist with their adjustment. Changes to philosophy of life and interpersonal relationships were more prominent than perception of self. Discussion of the results suggests the importance of providing individualised, flexible services for carers which may include support groups facilitating growth.

3.1 Introduction

The impact of caring for someone with an acquired brain injury (ABI) has been much discussed in the literature and beyond. The Department of Health is due to publish a National Service Framework (NSF) for long-term conditions in 2004. Long-term conditions cover the needs of people with neurological disease and brain and spinal injury. A key theme for the NSF will be the needs of carers; the report from the scoping event recommended *‘anticipatory, pro-active care and support for carers to prevent them “going under”’* (Department of Health, 2001). In addition, the British Psychological Society (BPS) highlights a role for clinical psychologists in supporting the carers and family of stroke survivors (BPS, 2002).

The repercussions of caring for a family member with ABI can be diverse in both their nature and consequences (e.g. Man, 2002; Marsh, Kersel, Howill & Sleight, 1998; Oddy, Humphrey & Uttly, 1978). In their study of people caring for older adults, Orbell and Gillies (1993) suggest there are two main categories of demands placed on carers. The first demand is from providing assistance with activities of daily living, such as shopping, toileting and dressing. The second demand relates to cognitive decline, requiring the carer to attend to, or actively monitor, the person being cared for continuously. Whilst they focused on older adults and this study concerns carers of people with ABI, there may be some similarities. Bowen, Tennant, Neumann and Chamberlain (2001) suggest that someone with ABI may

have poor tolerance for frustration, reduced insight and self-monitoring, fatigue, and disinhibition, which can be difficult for the carer to manage. Marsh et al. (1998) found an almost inverse relationship between the frequency of problems in people with ABI (for example cognitive impairment, emotional or physical difficulties) and the degree of distress in their caregivers. Social isolation was reported as causing the most stress for their participants. As isolation tends to increase over time, so may the levels of distress experienced. They found clinically significant levels of anxiety or depression in just over one third of their sample (Marsh et al., 1998).

A carer's appraisal of the symptoms resulting from ABI determines the perceived severity and burden experienced by the carer (Knight, Devereux & Godfrey, 1998). It therefore follows that consideration of the subjective experience of carers is important to assessing their adjustment to caring, the demands placed upon them, and their support needs, in other words the way they are coping. This is supported by Oddy et al. (1978) who propose that the impact on carers may be mediated by their perception of personality changes and subjective deficits.

When conceptualising coping, Schwarzer and Schwarzer (1996) suggest that effort and cognitive appraisal are as important as actual behaviours. Coping consists of both resources and strategies. Coping strategies refer to behaviours occurring after the appearance of the stressor, or in response to

chronic stressors. The way people actually cope depends on the resources available to them and the constraints inhibiting them (Lazarus & Folkman, 1984). Pearlin and Schooler (1978) suggested that coping resources are particularly helpful in situations over which people have little direct control and may buffer the effects of stress compared to coping strategies. Coping resources specifically may therefore be of importance to carers, who often have no control or choice over accepting or continuing with the role.

As previously stated, an individual's reaction to caring may vary greatly. People experience a range of negative outcomes or may cope successfully. For some people trauma facilitates individual development or growth. This post-traumatic growth (PTG) is both a process and an outcome. It develops out of a cognitive process initiated to cope with traumatic events that evoke an extreme cognitive and emotional cost (Tedeschi, Park & Calhoun, 1998). Tedeschi and Calhoun's (1995) model suggests that the initial response to trauma is characterised by unmanageable distress, which triggers rumination processes. These rumination processes are followed by an initial stage of growth and then a final stage of growth and wisdom (Frazier, Conlon & Glaser, 2001). This suggests that growth and benefits may increase over time. Davis, Nolen-Hoeksema, and Larson (1998) found that early reports of positive change predict subsequent recovery; however change can fluctuate over time with highs and lows, which may lead to increased levels of distress. In their study of sexual assault victims, Frazier and colleagues

(2001) found that positive changes generally increased and negative changes generally decreased over time, consistent with current theories (e.g. Tedeschi & Calhoun, 1995). In relation to carers of people with head injuries, negative changes and strain have been found to increase significantly over time, from first to fifth year post-injury (Brooks, Campsie, Symington, Beattie & McKinlay, 1986).

Whilst a significant proportion of research has focused on coping and negative consequences for carers, some researchers have investigated positive aspects. Two studies concerning carers of older adults found participants reported at least one positive aspect of care-giving. They concluded that positive feelings about coping were associated with lower depression and burden scores (Cohen, Colantonio & Vernich, 2002) and may be indicative of quality of care (Orbell, Hopkins & Gillies, 1993). Knight et al. (1998) found that satisfaction with ability to cope was predictive of depression scores. Nolan, Grant and Keady (1996) describe the satisfactions of caring in three dimensions: satisfactions from the interpersonal orientation of the carer; the interpersonal dynamic between carer and cared-for person; and the desire to promote a positive or avoid negative outcomes for the care recipient. These dimensions appear to be similar to the life domains in which PTG is reflected, namely in perception of self; interpersonal relationships and philosophy of life (Tedeschi et al. 1998).

Although positive changes and PTG may be present in carers, the extent and experience may be qualitatively different. The majority of PTG literature has studied people following trauma such as abuse or loss of a loved one. There is a conceptual difference between such populations and carers, as for carers there is no immediate end to the trauma and their role may continue for years. It could be argued that experiencing ABI in a family member is traumatic, but in addition the situation is continuous and subject to change due to health or age related factors, among others. This suggests that for carers, trauma is both the event and the sequelae. The result is a process of adjustment which takes time and may need to be revisited on different occasions.

In addition to individual differences between carers due to personal factors, there are also differences in response to caring dependent on their relationship with the injured person. Parents and spouses caring for people with ABI have different vulnerabilities to stress. Spousal care-givers are required to confront and adjust to a marital relationship in which they have to make many decisions on behalf of their husband or wife. The running of the home and payment of bills are responsibilities that they may now have to perform, particularly in the case of older wives taking up the caring role. Many spousal caregivers stay in the marriage relationship solely from a concern for the injured spouses' future (Degeneffe, 2001). When measuring care-giver burden, Allen, Linn, Gutierrez and Willer (1994) found that

although spouses and parental caregivers reported comparable levels of burden, there were qualitative differences. Parents reported concern for the future of the person with head injury, whilst spouses reported fewer positive feeling than the parents group. Marsh et al. (1998) suggest that while marital relationships are not necessarily more vulnerable to the effects of care-giver burden, those relationships that are affected may be so to a greater degree than other types of relationship.

Research on the impact of caring for a family member with ABI has emphasised the use of objective studies. This has concentrated on measuring observable phenomena for the person with a brain injury such as the extent of physical care needs, and for the care-giver, for example changes in social activities, as a means of indicating levels of stress and burden. There has been less qualitative research exploring carers' perceptions of stressful events encountered during care-giving (Degeneffe, 2001) and their experiences of being a carer. As discussed, the subjective experience and satisfaction with caring are predictive determinants of the well being of the carer.

There are various terms used in the literature to describe the impact on carers, such as burden, stress and strain, often without comprehensive definitions. By imposing such terms and constructs on the questionnaires completed by carers, the results are limited to the pre-determined concepts,

and therefore, whilst being of some use, may not actually tap in to the specific experiences of the carer and key factors may be missed. The definition of the 'main' carer, as used by many studies, does not give information as to whether they are the sole care-giver or to the demands placed on the carer, which are important factors in carer well-being. The ideas of care-giver gain and positive aspects are expanding in the literature, but lack of conceptual clarity and psychometrically sound measures may be limiting advances in this field of knowledge (Kramer, 1997). It may be useful to start with the reported experiences and feelings of carers, in order to inform future research and clinicians which concepts reflect carers lives most accurately.

The literature suggests that the subjective experience of carers is important, and that the experience of spouses may differ qualitatively from that of other family carers. It would be helpful to know more about carers' actual experiences and how they perceive their lives as having changed, in other words how participants make sense of their personal and social world. In a previous study (Deane, Cushway & Joseph, 2004 in this volume) wives constituted a significant proportion of the participants. Therefore the aim of this study is to use interviews to explore the experience of being a wife for someone with ABI and consider whether it is useful to use PTG as a framework to enable adjustment and acceptance of their changed life.

3.2 Method

3.2.1 Ethical approval

Ethical approval to carry out this study was granted by Coventry University Research Ethics Committee in June 2003; Warwickshire Research Ethics Committee in July 2003, Coventry Local Research Ethics Committee in October 2003 and Hereford and Worcester Local Research Ethics Committee in November 2003 (Appendix A).

3.2.2 Participants

In a previous study (Deane, Cushway & Joseph, 2004 in this volume) carers were asked if they would consent to participate in the interview study, if selected. All the wives who responded did consent to be interviewed. The first six wives who fitted the criteria were selected. The criteria were wives within working age who were caring for their husband at home. Therefore one wife was excluded as she was caring for her husband, but he lived in a nursing home. The interviewees ranged in age from 50 to 65 years, the average was 56.8 years. They had been looking after their husband for an average of 6 years 4 months, although this covered a wide span from a minimum of 12 months to 17 years and 5 months. Four of their husbands had suffered from at least one stroke, one husband had suffered a traumatic brain injury from a car accident and one had had a subarachnoid haemorrhage.

3.2.3 Data collection

Participants initially became aware of the research due to completing questionnaire measures for another study (Deane, Cushway & Joseph, 2004 in this volume). The information sheet informed participants of the interview element and participants were asked if they were willing to be interviewed on the consent form (see Appendix C & D). From those who agreed to be interviewed six wives were selected as fitting the criteria. These people were sent a letter asking if they were still willing to participate. This was followed up with a telephone call to arrange the interview. The interviews were all conducted in the participant's home and recorded on cassette. A separate consent form was used for this (see Appendix D). The interviews lasted between 30 and 90 minutes each. A semi-structured interview was used asking about how their lives have changed and included the areas where growth has been reported in the literature (perception of self; interpersonal relationships and philosophy of life). Some emphasis was placed on the process of change, whether it developed over time, if they could identify what facilitated any changes, and coping strategies they have found to be helpful or less helpful (see Appendix F for schedule). As the interviews were semi-structured, the schedule was not followed directly, but used as a guide for areas to be included. At the end of the interview participants were given the opportunity to share any other information they felt relevant.

3.2.4 Data analysis

The interview transcripts were analysed with thematic analysis using Interpretative Phenomenological Analysis (IPA). The guidelines of Smith and Osborn (2003) provided a framework to facilitate the identification of shared experiences across the participants. In IPA the meaning is central, with the aim of understanding the content and complexity of meanings, rather than frequency (Smith & Osborn, 2003). The approach is phenomenological in that it involves detailed examination of the participant's life-world and attempts to explore personal experience and an individual's personal perception or account of an event rather than an objective statement of the event. The analysis requires extended engagement with the text and a process of interpretation. The following steps were followed:

1. The transcript from the first interview was read several times. Anything that appeared to be significant or interesting to the lead author was annotated in the left-hand margin. Notes included summaries, paraphrases, connections, contradictions and preliminary interpretations.
2. Initial notes were then transformed into succinct phrases with the aim of capturing the essential quality of what was said in the text. These were recorded in the right hand margin and took the form of emerging theme titles. At this stage the notes had strong connections to the original text, whilst they may have been of more psychological terminology.

3. Emergent themes were listed on a sheet of paper. Connections were looked for and emerging themes clustered together according to analytic or theoretical ordering rather than chronologically.
4. The clusters were checked in the transcript to ensure applicability. To aid this process a list was compiled of participant phrases that related to the themes.
5. A coherent table of themes was produced and clusters were given a name, these represent the sub-themes. The sub-themes were further drawn together at a higher level, representing master themes.
6. The transcript from the first interview was both lengthy and contained rich data. Therefore it was decided to use these themes to inform the analysis of other transcripts. Whilst analysis of subsequent transcripts looked for repeating patterns and incidences of the identified themes, new issues were also highlighted. The aim was to identify convergences and divergences in the data as a whole, recognising similarities and differences between individual interviews.
7. Although no new master themes were identified, new sub-themes were identified, or existing sub-themes were amended. Following this,

preceding transcripts were then revisited to look for presence of the updated sub-themes.

8. The coding and analysis of the transcripts were discussed with colleagues familiar with IPA to enable verification of the themes and possible interpretation of the data.
9. Consultation with colleagues and the second author led to adjustment and development of the themes, for example the renaming of themes or incorporation under a joint name.
10. The most prominent master themes and sub themes were written up, using extracts for illustration. Prominence related to judgements of frequency and importance in the transcripts. All names of participants and their husbands were changed to ensure anonymity.

See Appendix G for examples of steps of the analysis.

3.2.5 Author's experience and values

In thematic analysis, the researchers are faced with the challenge of reporting the data without imposing their own values or assumptions (Woodward & Joseph, 2003). However, the use of thematic analysis recognises the impact of the researcher on the research process, in respect

of the need to make sense of, and interpret, the participant's personal world. It is impossible to entirely remove one's perspective from analysis (Elliott, Fischer & Rennie, 1999); further in IPA the researcher has a central role in making sense and interpreting the participant's experience (Smith, 2004). Therefore it is helpful to provide an overview of the lead author experience and assumptions prior to approaching the data.

The lead author, Teresa Deane, has experience working in the field of neurological rehabilitation both as an Assistant Psychologist and as a Trainee Clinical Psychologist. In both positions consideration of the needs and influence of the main carers was required. The experiences led to realisations regarding the resource restrictions in offering services to carers. In addition the lead author is a volunteer for the local branch of a head injury charity. On a personal level the lead author had experience of elderly relatives being cared for at home. This resulted in some awareness of the responsibility and continuous nature of the role. The main analysis was carried out by the lead author then discussed in supervision and with an IPA support group of colleagues.

3.3 Results and discussion

Table 3.1 Themes identified in the transcripts

Master themes and sub-themes	Number of participants with theme
1 Adjustment	
• Maintaining Self	5
• Previous life	6
2 Relationships	
• Intimacy	6
• Valuing people	6
3 Quality of life	
• Appreciation of life/situation	6
• Priorities/Approach to life	6
4 Influences on Change	
• Situational	5
• Path towards Understanding	5
5 Perceived Coping	
• Comparison and Compassion	6
• Use of Coping	6

3.3.1 Theme 1 – Adjustment

Maintaining Self

This refers to a process of coming to terms with the role and life they now have. Participants conveyed a feeling of a continuing struggle to incorporate aspects of the new role they are less comfortable with, into their sense of self. The theme reflects participants striving for control and reflects their resiliency.

Diane

“it could have been so easy for me over these past 2 years to have gone down a different path really and become quite depressed, withdrawn, and, and that’s what the majority of people say to me, they say how do you cope”

Anne

“I like things to be sorted and I like to know it’s going alright, but I never expected to have to take over completely”

Emily

“he’s always been more outgoing than I have, I’ve managed to help him keep that up, because that in turn, um, gives me a bit of leeway, we’ve always done a lot of things together”

The examples appear to convey an element of choice, albeit somewhat unconscious. There is an acceptance of what they need to do in order to

survive and how they are going to achieve it. When talking about how they have changed, the acceptance of a caring role seemed to result with initially the necessity of the wives placing their needs behind those of their husband and their family.

Previous life

Participants referred to a cognitive process of recognising the similarities and differences to their previous life, and calling on previous coping strategies. This seems to involve participants reflecting on past experiences and family scripts. The process involves recognising how things were, what worked in the past and what had to change.

Carol

“the relationship has, changed, and I suppose it did right from day one, it had to, things were never going to be the same again, but, they were quite similar to start with, but then, they weren’t”

Frances

“but we were brought up in a big family and you look after each other, and you have to tough it through”

Diane talked of similarities between her approach to life and her mother's:

Diane

"we're very similar in a funny sort of way, whatever life throws at you, you just get up and get on with it"

Part of adjustment to change requires a re-evaluation of life. Experiences are viewed in light of current limitations and previous patterns of coping.

Kosciulek (1997) found that family schema was related to family adaptation.

By schemas he refers to beliefs, values, goals, priorities and expectations, which are often set down in an individual's upbringing and family values.

3.3.2 Theme 2 – Relationships

Intimacy

The participants talked of how their relationships had changed, with their husbands as well as friends and family. This was raised both in response to direct questioning regarding changing relationships and independently at other points during the interview. The participants could recognise that the dynamics of their relationships had changed, and that there were now new aspects that they appreciated such as increased closeness and understanding.

Anne

"I understand him and he understands me and it's worked out ok, we've both, got lots of patience, I think that makes a big difference"

Carol

"I'm much more open with him now than ever I was before and it took me a long time to be as honest and open as I am"

When asked about her relationship with her husband, Diane said:

Diane

"Much, much closer, err, we talk a lot more than we did before, um, and I think we understand each other a lot more"

Calhoun and Tedeschi (1998) describe people experiencing an increase in interpersonal and emotional closeness following trauma as well as a perceived increase in freedom to express emotions. This is demonstrated in the participants' comments. Part of this closeness and understanding was related to dealing with the potential loss of their husband, but also related to the fact that it is only those in the immediate family who fully understand how their lives and their husbands have changed. This shared knowledge and understanding is part of the closeness and bond within the family.

Valuing people

The participants talked of how important good friends were in their lives. They referred to the need to be able to rely on people and value their help and support. They also spoke of changes to their circle of friends. While some friends faded away over time, other people became new or closer friends.

Frances

"if it wasn't for, you know, the family I don't know what I'd do sometimes, really don't, well, I've been in screaming pieces a few times aint I, and they've said go on out, go out for a bit, it um, it's calmer that way"

Carol asked her neighbour for help with her car, a job previously done by her husband:

Carol

"he said you know I'd do this all the time, I said, no I don't need you all the time, as long as you're there when I do need you, that's the main thing, and that's fine"

Some participants talked of carer support groups. The impression given was that they had value, but it was useful to be able to 'dip in and out' dependent on how they were feeling and their changing needs.

Emily

“we’ll have days out at nurseries, and go and look at plants or, we might go round a museum, go for a coffee, so it’s a support group within itself”

The participants appeared to be experiencing an internal battle between the need to be self-reliant and capable, with recognising when they need help and support. The participants talked of receiving support in the form of social support from friends and family or more professional support, such as support groups or anti-depressants. Over time, those who report PTG often develop this sense of strength where they can recognise their own vulnerability, producing assertiveness to seek useful support and reject that which is less helpful (Tedeschi et al, 1998). Social support has an important role in coping and life satisfaction (Grant, Elliott, Newman Giger & Bartolucci, 2001). Participants talked of the shared understanding with other carers. This may be similar to the understanding within their immediate families. The experience of other carers and their individual situations provided some perspective and appreciation for their own particular circumstances.

3.3.3 Theme 3 – Quality of life

Appreciation of life/situation

Whilst there was an acknowledgement that their current situation is not one of choice, they were all able to identify positive aspects of their current situation and appreciate the life they now lead. There was reference to the

importance of a balance between the needs of their husband and family and maintaining their own well being.

Anne

"we've got a far better quality of life than people, than we would have done"

Becky

"we still can do most things that we've always wanted to do, but, you know, at a slower pace basically"

"I've sort of found a nice balance, which, with sort of caring for Andrew but also having other interests for myself and it works very well really"

Carol

"in fact, in some ways perhaps it's done him good, you know his attitude has changed for the better in some respects"

These comments reflect an appreciation and acceptance of current life.

Finding meaning by considering the positive implications may help to minimise the negative implications (Davis et al., 1998).

Priorities/Approach to Life

Participants described a slight alteration in their approach to life and consideration of priorities. Several participants referred to living in the present rather than waiting for future occasions; this philosophy is captured

by some of Diane's comments about the way she spends her time and her thoughts about working in the future:

Diane

"I want to spend the summer in my garden, and I want to be in my home and I want to sort of spend as much time with him as possible and things like that"

"I think then I'm permanently reassessing what I'm doing, all the time"

"what was important to me before probably isn't so important to me now, so my values have changed, a lot"

A greater appreciation for life in general, and in particular the smaller things (Tedeschi et al., 1998), can result in people wanting to spend more time with the people they care about and lead to a change in values. Diane referred to previously being driven and influenced by the status she attached to her job, whereas now she is considering a future where employment is simply a way of earning money, rather than reflecting who she is.

3.3.4 Theme 4 – Influences on change

Situational

Most of the participants talked of changes over time being influenced by a range of factors. These factors had led to changes in their perception of

themselves and the situation as well as their perceived coping. The impression given by participants was that this process is ongoing.

Changes and improvement in their husband's health and rehabilitation were important:

Carol

"at first he wasn't walking, so that had it's own problems, and then when he started to walk that created different problems"

Changes to their circumstances led to problems easing, but also the opportunity to gain new roles or re-establishing previous roles important to their sense of self. An example is Emily's husband getting his driving licence back:

Emily

"it's improved slightly in the fact that my husband has now got his licence back so we can get out, before that it was very difficult (. . .) it's helped with him having the car again, um, so we've been able to be supportive to other people."

Changes over time were attached to specific events or developments, but also to a more general overview of improvements:

Becky

"he's a lot better now, he will try and do things now, whereas he used to just sit in the chair most of the time unless I said go and do something, but he will go and do things of his own accord now"

Their husband's abilities, progress and needs were quite central to how participants viewed their own coping and success. These observable changes provided markers with which the carers could rate their functioning.

Path towards understanding

Of importance were the more internal changes to the way participants consider the situation. This reflects the use of a new wisdom on the way they view their life and how they want their lives to be. There was a general feeling that participants were trying to make sense of what had happened to their husbands and why. They made comparisons to alternative situations, trying to apportion blame for the injury and also trying to make sense of the resulting deficits in their husbands. The focus is slightly more on understanding of the situation than understanding themselves.

Diane

"it's the first time I've ever confronted the fact that I could be facing sort of everything without him, in a funny sort of way it makes you stronger, sort of, it makes me definitely more aware, because I confronted it and I thought I wouldn't know what to do, if he had of, gone, or whatever, and I think that, um, definitely has made me look at things differently"

Anne

"in some ways it might have been better if, he's often said he wished in a way that he'd had a physical injury, say his arm didn't work, but his head was fine, but it's, that's how it is"

Carol

"I started to resent him, you know, that, um I kept thinking well why's he done this, why have you done this to change the life that we had, why, why did we have to do, you know why did you have to go through this just to get change in your life you know, this isn't the way to do it, and then I thought, no, it's not his fault, it's obviously not his fault, but I still resented the changes that we had to make, um, I still resent the changes we've had to make in the house"

“I worked with a lady, she’s younger than me, she was only 41 when she lost her husband, and he was the same age, um, so, I always said to her that I had lost my husband the day he had the stroke (. . .) we had an awful lot in common, you know, the grieving process was very similar, um, but when she went through hers I could actually see her through it, because I knew what she was feeling, although I could come home to my husband every night, and she couldn’t, there were big similarities”

It has been proposed that for successful adaptation, it is necessary to first make sense of the event, then find some benefit or value in the experience for your life (Davis et al., 1998). These examples show a movement towards greater acceptance and understanding of the situation.

3.3.5 Theme 5 – Perceived Coping

Comparison and compassion

The participants were open regarding the acknowledgement that their situation was not how they envisioned their life would be, or what they wanted. However, the participants felt that in general they were coping fairly well and in comparison to some others they were coping better with regard to being a carer and maintaining their marital relationship. One way this is reflected is in expressions of compassion towards others.

Carol

"I'd like to know, in a way, how different carers can be, because I'm sure they're not all like me, not by a long shot, um and I know a fair few, but, most of the women that I know that do the caring have got very similar attitudes to me, about getting on with things"

Diane

"people who have so much more to contend with than him everyday, and I, you know, I look at them and I think, oh my god you're so brave, you're so, good, you know, to keep on functioning, and they battle through life everyday, don't they, with far more disabilities um, than David, it's made me very aware, people like that"

The transcripts contain many references to comparisons. These were in relation to how life had been; how they hoped life would have been; to other people or relationships, and also to having to treat their husband similarly to how they had dealt with their children when young.

Becky

"there's so many people now that have problems, there's so many, almost every other family seems to have some sort of problem don't they, either they've had an accident or they've got an illness, or, or they've split up, or something"

This process of comparison seemed important to re-evaluation of their lives and a necessary part of moving on with their lives and successful coping with being a carer. There appeared to be a necessity to place themselves within the context of others.

Use of coping

Participants referred to a range of both practical and psychological coping strategies. There was an emphasis on helping their husband to feel useful, with an aim of not drawing attention to his difficulties. The general atmosphere created was of knowing that there is a way around everything, it is just necessary to consider the situation from a different angle.

Organisation and routine are important aspects of current life.

Anne

“but you just have to organise just about every little bit of the day, but, to a point you’ve got to try to make it that you’re not doing that, and that’s the hard bit”

Emily

“So it’s really keeping on the positive side, alright you can’t do something you’d like to, but there’s something else that could take over from that, it’s a bit of lateral thinking as well”

Carol

"we have to have a routine now, whereas, life before the stroke was a routine of a different sort"

The participant's views reflected successful coping, drawing on both resources and strategies.

3.4 General discussion

The results suggest that these women are adjusting to, and accepted the role of carer. They have drawn on previous strategies and adapted to maintain their own well being whilst attending to the husband's needs.

Comparison was an important part of this process. Components of PTG and positive aspects could be identified and may have aided the process of adjustment and acceptance.

The results suggest that aspects of PTG provide a useful framework to consider the experiences of being the wife of someone with an acquired brain injury. The view of PTG being both a process and an outcome is reflected here in that the wives have not reached the end of their journey.

Although all three components of growth (perception of self, interpersonal relationships and philosophy of life) can be identified, these results suggest that the participants place slightly more focus on changes to philosophy of life and relationships than to their perception of self. When a caring role is undertaken, the necessity of focusing on care and putting the needs of their

husband and family first may be a priority. All the participants were mothers and compared the experience of being a carer to having complete responsibility for someone, as with a young child. In addition wives may feel a sense of responsibility and duty towards the man they love and chose to spend the rest of their lives with. This may result in the wives' thinking of changes to their sense of self less than changes that may also impact on other people.

The analysis process involved reflection of the themes presented and the impact of the lead author on interpretation. Consideration was given to whether the themes were truly representative of the data or slightly moulded to fit the expectations of the lead author. It is acknowledged that IPA is interpretative and therefore analysis of the same transcripts by someone else would most likely produce different themes. In support of the current analysis, whilst the interview schedule does reflect areas of growth, in the interview these were presented in a neutral format with the aim of not influencing participants towards a desired response. Reflecting on the interview and analysis process identified feelings of admiration for these women and the way they had adjusted to their new life. The self-reliance and determination of participants resonated with values the lead author would like to convey in herself. The analysis has attempted to reflect the attitudes and inner strength of the women interviewed, as experienced by the lead author.

The analysis presented is based on the interpretation of the lead author following discussion in supervision and with colleagues to address the reliability of themes identified. An additional source of reliability would have been obtained by sending the themes with descriptions to the participants for comment. It would be interesting to know how well the participants identify with the themes presented here and hear their comments. Participants will be sent a summary of the study and results.

This study is based on the experiences of six women. Whilst comparisons have been drawn between their experiences, the degree to which these results can be generalised to all carers or even all wives who care for their husbands is limited. The perceived success in coping was present in all those who did participate, which has influenced the emphasis of interpretation. The sample were fairly homogenous in that they had all been married a long time and their children were adult, the youngest being in their late teenage years. In addition to the caring experience being different for spouses to other family members, the length of marriage and stage of life at which marriage occurs may also be important factors to adaptation. In addition to the duration of marriage being an influential factor, the duration of being a carer may be important. The length of caring in this study covers a wide range. Whilst the themes identified reflect most powerfully in the

majority of transcripts, there may be subtle differences over time or stages of growth may have been missed by this analysis.

The results indicate the need for an individualised, flexible service being offered to carers including both emotional and practical support. Being self-reliant and coping without external support were reflected as important to the carers interviewed in this study. An implication of this may be that carers will be reluctant to ask for support. Reinforcing the concept that accepting support demonstrates inner strength rather than weakness may be required. Therefore services should be sensitive to the overall presentation of the carer as well as what the carer actually reports. In addition to services being flexible according to need, flexibility of time is also encouraged. The needs of the carer may vary over time dependent on changes in their husband's health and needs. Their needs may also vary dependent on their appraisal of their caring abilities or the expectations they hold. Expectations related to improvement in their husband's health, their role or quality of life may not be met over time and lead to increased stress levels or carer mental health problems.

The use and value of social support was mentioned by the participants as well as attending carer support groups. At present there is not sufficient evidence connecting the role of social support to the facilitation of growth. What is clearer is the importance of rumination over time leading to

experiences of growth and positive change. This supports the suggestion of support groups as a forum for rumination. When considering the clinical implications of this study, the limitations of resources for working with carers must be taken into account. It may be that resources could usefully be employed in the form of support groups with the aim of facilitating growth. The concept of growth in the carers' perception of self may be a useful intervention and focus for a group.

Future research may look in more detail at the experience of growth over time in carers and what influences changes. It would be interesting to produce a model of the stages of change and identify whether there is an optimum time for intervention. This study does not identify what the most important factors to change are, whether time, changes in husband's health or personal characteristics of the wife are the most influential on changes. The role of family and social support and how these are interpreted and used by wives is not fully understood. Responses of others can play an important role in adjustment. Further exploration of the positive and negative impact of friends and family would be beneficial. Whilst qualitative methods are useful for understanding the individual experiences unrestricted by pre-determined questionnaires, there is value in the use of these experiences to develop new measures that relate to concepts identified by carers. This would enable larger studies to be conducted which would increase generalisation of results.

In conclusion, this study describes the experience of adjustment, growth and coping in wives caring for their husbands who suffered ABI. Previous coping strategies and experiences were necessary to successful adjustment.

Changes to interpersonal relationships and re-evaluating priorities were emphasised by the wives. The results suggest the role of support groups for facilitating growth. The role of social support in facilitating growth is an area requiring further investigation.

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Researcher, practitioner and me: How do they fit together in a thesis?

The purpose of this review is to present some personal reflections on writing a thesis for a Clinical Psychology Doctorate. The review will cover considerations of why I chose the topic areas. In addition there are thoughts on the research process, in particular the process of conducting interviews and the relative merits of different approaches to research. Some clinical implications from the research are also discussed.

4.1 Area of interest

The two empirical papers concerned carers of people with acquired brain injury (ABI) and post-traumatic growth (PTG). The literature review explored the unconscious motivations which lead to choosing a caring profession, in particular psychological therapists and how personality may impact on the role. Whilst the two areas appear to be very different, there was a journey that led to this combination. I am interested in how people cope and conceptualise the caring role thrust upon them when a family member becomes ill. Consideration of this prompted thoughts related to those people who actively choose to care for a profession, and in particular the career I had chosen. Therefore it seemed to be a small leap to include consideration of both informal and professional carers within one thesis.

When writing my literature review I spent time reading the literature on family of origin, wounded healer and psychologist's personalities. This led me to consider my thoughts in relation to these concepts. My mother always jokes to people that I'd chosen to be a psychologist to sort out my parents, and I started wondering to what extent this was true. This is something I'd spent time reflecting on throughout the training course and had explored in Personal Development Group. I found myself being confused by what was my memory and what memories had been reinterpreted by my subsequent knowledge. Whilst writing my literature review I was constantly aware of the fact that the research was retrospective and self-report, therefore subject to considerable selective recall, filtering and reconstruction, in a similar way to my memories. After considerable thought the conclusion of my literature review was that whilst it is important to spend some time thinking about the past and personal vulnerabilities, and acknowledging they have some influence on current thinking and functioning, it is equally, if not more important to live in the present and plan for the future, watching out for how we are coping and functioning now, whether we are sufficiently supported, monitoring our efficiency and effectiveness and avoiding burnout. I realised that I needed to apply this to myself, both while writing the thesis and beyond.

The empirical papers explored the experiences of being the main carer for someone with ABI, such as head injuries, stroke or haemorrhage. ABI is an

area that particularly interests me due to its sudden onset or occurrence, often without warning. I am struck by the fact that life can change so entirely in such a small amount of time. There were several reasons why I chose the focus as carers. Firstly, life is also changed for them from that same point in time. Secondly, the people with acquired brain injury are generally spouses, parents or children and therefore carers do not feel they have a choice in accepting the role that they do not want, nor do they have the experience for managing it. Thirdly they have a vital role in the rehabilitation and continued well being of the person with ABI, and finally, from prior experience I was aware that often the help and support they need is not available, often due to resource issues. More personally, when younger my mother had cared for elderly and infirm members of my family at home, so I knew of the continuous role and responsibility of caring. I am motivated by wanting to let carers know that I value what they do and remind professionals of their needs.

4.2 Conducting interviews

This was the first time I had used qualitative methods in research and carried out interviews of this type. Initially I was pleasantly surprised that people were so willing to take the time to talk to me and invite me into their homes. Of the six interviews I conducted, each was a very different experience and something always happened that I had not previously considered. One interview I found particularly challenging from a set-up point of view was

when I was interviewing a wife whose husband had been in a car accident. He wanted to sit in on the interview, their daughter was sat at the other end of the room breastfeeding her young baby and there was a budgie in a cage directly behind the woman I was interviewing merrily chirping away throughout! This was the second interview I conducted and I was still finding my feet. Whilst the wife was happy to talk to me in this situation, I can't help but wonder how this impacted on what she said. However I did learn from this situation, by my last interview I had gained the confidence to insist that it would be better to go into another room rather than sit with her husband, sister, brother-in-law and the television on. I had to settle for her sister being present and commenting during the interview, but I felt this was a compromise I could work with.

My nature is to try to help people, share information and offer advice. I found it very difficult to refrain from 'being a person' as I was in their home, or 'being a therapist' in order to concentrate on 'being a researcher'. Whilst my therapeutic skills were invaluable in helping people expand on what they were saying, reflecting back and encouraging them to talk, it felt quite alien not to help them move on with their thinking or help them problem solve. One thing that was striking from all the interviews was the way they all felt they had to battle to get support and be resourceful to find out what they were entitled to and what support was available. This included medical help and medication issues. This left me feeling embarrassed on a personal and

professional level as they described this struggle and the lack of help they receive. The lack of information they were given was notable. I felt uncomfortable that they had this ongoing struggle in addition to adjusting to their new responsibilities and role and felt more could be done.

4.3 Clinical implications

Considering both the interview and questionnaire data from my thesis I became very aware that potentially my sample may be biased. It may be over-represented by those who felt they were managing to cope and who had the personal resources to track down the support that was available. This left me wondering about what happened to the people who are less resourceful, who don't have the confidence to keep contacting places, or people who may have strong values related to looking after one's own family without help. The low response rate to my questionnaires (16%) left me feeling that whilst the non-responders will cover a variety of people with a range of adjustment and coping skills, there could be a large number who are struggling. This may have huge impacts for the person they are caring for and could possibly end in a crisis situation. The old saying about prevention being better than cure sprang into my mind. One woman I interviewed suggested giving people a pack when they leave hospital containing the telephone numbers of who to contact regarding services, benefits and charities. It seemed such a simple idea, there must already be people who have this information, or know how to find it. The time of

discharge from hospital must be a very difficult time with an uncertain future, when the capacity to absorb much information, or know what help and support that a carer may need on future occasions is difficult to judge. Therefore a resource pack that could be referred to at a later date seemed useful.

The wives I interviewed all referred to support of varying types. Social support was important. This was referred to in respect of how supportive existing friends and families were. In addition the interviewees made comparisons to other carers they had contact with. The comparisons were made in a favourable way, highlighting the vast array of difficulties following ABI and how people manage their lives. One thing that I found of particular note was that several of the wives I interviewed were interested to know how other carers were managing, and how their success at coping compared. For those who had attended carer support groups, the general consensus was that they were beneficial. Support groups were seen as sources of support and understanding as well as places to gain or share knowledge. There was however, also the idea that the benefits may vary over time, and that it is useful to be able to 'dip in and out' according to individual need. This was particularly important for the first few years. In addition to these components being valued, the social aspect of support groups was important and as a release from the responsibility of caring, even for a short time. If considering

interventions with carers, the implementation of carer support groups may be of value to the carers and considerate of restricted resource issues.

4.4 Qualitative vs. quantitative research

When designing my thesis I considered the most appropriate way to answer my research questions. A deliberation of the attributes of qualitative and quantitative approaches resulted in a thesis encompassing both. The questionnaire data provided me with results with which hypotheses could be tested statistically, resulting in conclusions that could be generalised. In the qualitative study the women I interviewed were all willing to share their stories with me. The richness of data which resulted gave me a real flavour of what life was like for them, which was lacking from the questionnaire data. This also seemed to be felt by some of the participants who completed the questionnaires. A few people added letters or additional information which they felt was required to provide a context for interpreting their questionnaires. While I have been carrying out my thesis I have reflected on my role in the process and how comfortable I feel with different approaches to research. The process of attempting to understand the personal experiences of individuals is familiar to me as a clinical psychologist and part of the initial attraction of the career. However, the process of writing up a qualitative study is unfamiliar to me. Whilst appreciating the interpretative nature of the approach, I felt personally on display and vulnerable. I have often felt uncomfortable showing a placement supervisor my reports and

letters, fearing my writing would expose inadequacies in my skills.

Interpretation felt like a very personal process, from which sharing the results can produce anxiety. On consideration, while quantitative research feels much safer for me as my interpretations can be hidden behind numbers and statistics to some extent; the journey in qualitative research promotes much more learning and self development.

I mentioned earlier the desire to be a voice for carers and remind professionals of their value and need for support. This feeling increased following the interviews. I felt great respect for these women and the way they coped. And so in summary, carers of people with ABI are a group of people I wish to defend and support. In addition I feel that the experience of conducting qualitative research is one in which I learn about myself in addition to the participants of the study.

Appendix A – Ethics letters

- **Coventry University Research Ethics Committee**
- **Warwickshire Research Ethics Committee**
- **Coventry Local Research Ethics Committee**
- **Hereford and Worcester Local Research Ethics Committee**

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: TERESA DEANE 2. Course: CLINICAL PSYCHOLOGY DOCTORATE
(BLOCK CAPITALS)

3. Title of project:

POSTTRAUMATIC GROWTH IN CAREERS OF PEOPLE WITH ACQUIRED

4. Summary of the project in jargon-free language and in not more than 120 words: BRAIN INJURY

Sample:

UP TO 120 INFORMAL CAREERS (MAINLY PARENTS AND PARTNERS) OF
PEOPLE WITH ACQUIRED BRAIN INJURY. RECRUITED AT CHARITY ORGANISATIONS
Research site: CAREER SUPPORT GROUPS

Design (eg experimental): EXPLORATORY QUESTIONNAIRE DESIGN

Methods of data collection:

QUESTIONNAIRES WILL BE DISTRIBUTED AT CAREER SUPPORT GROUPS WITH
PRE-PAID ENVELOPES FOR THEIR RETURN. QUESTIONNAIRES WILL BE
REPEATED BY POST APPROX. 6 MONTHS LATER.
A SMALL SUBSAMPLE OF 5 PEOPLE WILL BE INTERVIEWED FOR UP
TO 60 MINUTES FOR ANALYSIS USING QUALITATIVE METHODS

Access arrangements (if applicable):

- | | | |
|--|---|--|
| 5. Will the project involve patients(clients) and/or patient(client) data? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |
| 6. Will any invasive procedures be employed in the research? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 7. Is there a risk of physical discomfort to those taking part? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 8. Is there a risk of psychological distress to those taking part? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 9. Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |

Student's signature:

Deane

Supervisor's signature:

Stephen

Date:

04.06.03

FOR COMMITTEE USE:

Immediate approval

☒

Referral to local Hospital Ethics Committee

☐

Referral to full School Committee

☐

Decision pending receipt of further information
(specify below)

☐

Committee Member's signature:

Date:

David

11/6/03

WARWICKSHIRE RESEARCH ETHICS COMMITTEE

Lewes House,
George Eliot Hospital,
College Street,
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CV10 7DJ
Direct Line 02476 865244
Fax 02476 865058
E-Mail pat.horwell@geh.nhs.uk

10th July 2003

Teresa Deane,
7 Centaur Road,
Earlsdon,
Coventry
CV5 6LG

Warwickshire Local Research Ethics Committee
Approval Letter

**RE 583 Post traumatic growth in carers of people with acquired
brain injury**

Dear Teresa,

I am pleased to advise you that your application to participate as a Local Investigator in the above RE-approved study was reviewed by the Warwickshire Research Ethics Committee at their meeting on 30th April 2003 has now been approved. The Committee works in accordance with ICH/GCP guidelines

Please quote our RE reference number and title in all correspondence.

Yours sincerely


.....
Paul Hamilton (Chairman)

.....10/7/03.....
Date

**West Midlands South
Strategic Health Authority**
(Including Coventry, Warwickshire, Herefordshire & Worcester)



Hereford and Worcester
Local Research Ethics Committee

Please reply to:

Isaac Maddox House
Shrub Hill Road
Worcester
WR4 9RW

Chairman:

Mrs Carol Thompson B.Sc.

Ms Teresa Deane
Trainee Clinical Psychologist
7 Centaur Road
Earlsdon
Coventry CG5 6LG

Direct Line Number: (01905) 760091
Direct Fax Line: (01905) 733249
E-mail kath.garrad@sworcs-pct.nhs.uk

Our Reference: KG/
Your Reference:

27 November 2003

Dear Ms Deane

LREC: 03/111

Lead LREC reference number: RE583

Title: Post traumatic growth in carers of people with acquired brain injury

Papers reviewed:

- **Information Sheet, version 4, dated 14.11.03**
- **Consent Form, version 3, dated 14.11.03**
- **Indemnity letter The University of Warwick**

Thank you for your letter of 13 November 2003, received on 19 November regarding amendments to the above study. The Chair, acting on behalf of Hereford and Worcester LREC, has reviewed proposed amendments relating to the above study.

The Chair has agreed that there is no ethical objection to the proposed changes and she is, therefore, happy to say that acting on delegated authority of Hereford and Worcester LREC she has no objections on the understanding that you will follow the protocol and conditions, as agreed.

She did make the following comment:

- Consent Form, point 1, should refer to the Information Sheet dated 14 November 2003, version 4. Please therefore amend the Consent Form to Version 4 and give it a new date and send copies of both documents for our files on headed notepaper.

Your application has been given a unique reference number, please use it on all correspondence with the LREC.

Yours sincerely


Kath Garrad

Administrator, Hereford and Worcester Local Research Ethics Committee

An advisory committee to West Midlands South Strategic Health Authority

Chairman: Charles Goody
Chief Executive: Mike Marchment



Coventry Local Research Ethics Committee

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Email: pauline.pittaway@uhcw.nhs.uk

24 October 2003

Miss Teresa Deane
7 Centaur Road
Earlsdon
Coventry
CV5 6LG

Dear Miss Deane

Warwickshire REC Ref: 583
Coventry REC Ref: 10.6/10/03

Post-traumatic Growth in Carers of People with Acquired Brain Damage (Miss Teresa Deane, Trainee Clinical Psychologist, Employed by South Warwickshire Primary Care Trust) Part of Clinical Psychology Doctorate with the Universities of Warwick and Coventry. Fully approved by Warwickshire REC ref. 583.

I am pleased to advise you that your study, as detailed in the Health Authority Locality Form, has been reviewed by this Committee under the reciprocal arrangements between Coventry, Worcester and Warwickshire Local Research Ethics Committees and approved.

We shall send a copy of this letter and an endorsed copy of the Health Authority Locality Form to the Lead LREC.

Please quote the above reference numbers and title in all correspondence.

Yours sincerely

L J SANT CASSIA
CHAIRMAN
COVENTRY RESEARCH ETHICS COMMITTEE

Appendix B – Questionnaire Measures

- Demographic Information
- Brief COPE
- Post-traumatic Growth Inventory (PTGI)
- Changes in Outlook Questionnaire (CiOQ)
- General Health Questionnaire (GHQ), 12 item version

Demographic Information

Thank you for agreeing to take part in this study. The questionnaires should take approximately 15 minutes to complete. There are no right or wrong answers. Do not think too long about the exact meaning of the questions. Work you way through the questions quickly. I am interested in what your life is like since you have become a carer. Please answer the following questions about yourself and the person you care for:

How old are you? _____

Are you male or female? Male: ☐ Female: ☐

What is your current, or previous occupation? _____

If employed, do you work full, or part time?

Full time: ☐ Part time: ☐

What is your relationship to the person with acquired brain injury?

Can you describe what kind of support you provide (e.g. with personal care; emotional support; etc.)? _____

How old is the person you care for? _____

Are they male or female? Male: ☐ Female: ☐

What is their current or previous occupation? _____

What type of injury did they sustain? _____

When did they sustain an acquired brain injury? _____

Does anyone else live at home? _____

Do you receive any help or support from anyone else or organisations?

Brief COPE

I would like to ask you some questions about how you generally cope with stressful experiences in your life.

Please read each of the statements below and indicate, by circling one of the numbers next to it, recently, how much you feel you've been doing each item, from

0 – *I haven't been doing this at all to*

3 - *I've been doing this a lot.*

Please read each statement carefully, as some sound similar.

		Not at all			A lot
1	I've been turning to work or other activities to keep my mind off things	0	1	2	3
2	I've been making fun of the situation	0	1	2	3
3	I've been using alcohol or other drugs to make myself feel better	0	1	2	3
4	I've been accepting the reality of the fact that it has happened	0	1	2	3
5	I've been criticizing myself	0	1	2	3
6	I've been giving up the attempt to cope	0	1	2	3
7	I've been making jokes about it	0	1	2	3
8	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	0	1	2	3
9	I've been praying or meditating	0	1	2	3
10	I've been learning to live with it	0	1	2	3
11	I've been using alcohol or other drugs to help me get through it	0	1	2	3
12	I've been getting emotional support from others	0	1	2	3
13	I've been trying to come up with a strategy about what to do	0	1	2	3
14	I've been looking for something good in what is happening	0	1	2	3

15	I've been thinking hard about what steps to take	0	1	2	3
16	I've been getting comfort and understanding from someone	0	1	2	3
17	I've been trying to get advice or help from other people about what to do	0	1	2	3
18	I've been blaming myself for things that happened	0	1	2	3
19	I've been saying things to let my unpleasant feelings escape	0	1	2	3
20	I've been trying to see it in a different light, to make it seem more positive	0	1	2	3
21	I've been concentrating all my efforts on doing something about the situation I'm in	0	1	2	3
22	I've been trying to find comfort in my religion or spiritual beliefs	0	1	2	3
23	I've been saying to myself "this isn't real"	0	1	2	3
24	I've been getting help and advice from other people	0	1	2	3
25	I've been expressing my negative feelings	0	1	2	3
26	I've been taking action to make the situation better	0	1	2	3
27	I've been giving up trying to deal with it	0	1	2	3
28	I've been refusing to believe that it has happened	0	1	2	3

Please rate your ability to cope with the demands of supporting a person with acquired brain injury from:

0 = not at all satisfied to

4 = entirely satisfied

0 1 2 3 4

Post-traumatic Growth Inventory

Here are some questions about how your life may have changed since you became a carer. Please consider each statement below in terms of how becoming a carer has initiated changes in you.

Please rate as follows:

- 0 – I did not experience this change as a result of becoming a carer
- 1 – I experienced this change to a very small degree as a result of becoming a carer
- 2 – I experienced this change to a small degree as a result of becoming a carer
- 3 – I experienced this change to a moderate degree as a result of becoming a carer
- 4 – I experienced this change to a great degree as a result of becoming a carer
- 5 – I experienced this change to a very great degree as a result of becoming a carer

- ___ 1. My priorities about what is important in life
- ___ 2. Trying to change things that need changing
- ___ 3. A feeling of self-reliance
- ___ 4. A better understanding of spiritual matters
- ___ 5. Knowing that I can count on people in times of trouble
- ___ 6. A willingness to express my emotions
- ___ 7. Being able to accept the way things work out
- ___ 8. Having compassion for others
- ___ 9. Seeing new opportunities that would not have been available otherwise
- ___ 10. Putting more effort into my relationships
- ___ 11. Developing a stronger religious faith
- ___ 12. Developing new interests
- ___ 13. Accepting needing others

Changes in Outlook Questionnaire

Please read each statement and indicate, by circling one of the numbers next to it, how much you agree or disagree with it at present, since you became a carer:

- 1 – Strongly disagree
- 2 – Disagree
- 3 – Disagree a little
- 4 – Agree a little
- 5 – Agree
- 6 – Strongly agree

1.	I don't look forward to the future any more	1	2	3	4	5	6
2.	My life has no meaning any more	1	2	3	4	5	6
3.	I no longer feel able to cope with things	1	2	3	4	5	6
4.	I don't take life for granted any more	1	2	3	4	5	6
5.	I value my relationships much more now	1	2	3	4	5	6
6.	I feel more experienced about life now	1	2	3	4	5	6
7.	I don't worry about death at all anymore	1	2	3	4	5	6
8.	I live everyday to the full now	1	2	3	4	5	6
9.	I fear death very much now	1	2	3	4	5	6
10.	I look upon each day as a bonus	1	2	3	4	5	6
11.	I feel as if something bad is waiting around the corner waiting to happen	1	2	3	4	5	6
12.	I'm a more understanding and tolerant person now	1	2	3	4	5	6
13.	I have greater faith in human nature now	1	2	3	4	5	6
14.	I no longer take people or things for granted	1	2	3	4	5	6
15.	I desperately wish I could turn the clock back to before it happened	1	2	3	4	5	6
16.	I sometimes think it's not worth being a good person	1	2	3	4	5	6
17.	I have very little trust in other people now	1	2	3	4	5	6
18.	I feel very much as if I'm in limbo	1	2	3	4	5	6
19.	I have very little trust in myself now	1	2	3	4	5	6
20.	I feel harder towards other people	1	2	3	4	5	6
21.	I am less tolerant of others now	1	2	3	4	5	6
22.	I am much less able to communicate with other people	1	2	3	4	5	6
23.	I value other people more now	1	2	3	4	5	6
24.	I am more determined to succeed in life now	1	2	3	4	5	6
25.	Nothing makes me happy any more	1	2	3	4	5	6
26.	I feel as if I'm dead from the neck downwards	1	2	3	4	5	6

GENERAL HEALTH QUESTIONNAIRE

GHQ-12

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1	-	been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2	-	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3	-	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4	-	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5	-	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6	-	felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7	-	been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8	-	been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
9	-	been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10	-	been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11	-	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12	-	been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

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Published by nferNelson Publishing Company Ltd, The Chiswick Centre, 414 Chiswick High Road, London W4 5TF, UK.
This edition first published 1992.

Appendix C – Study Information Sheet

Version 4
14.11.03

Our ref

Study Information Sheet

Your ref

1. Title

Psychological Experiences of Carers of People with Acquired Brain Injury

2. Purpose of Study

This study suggests that the experience of acquired brain injury is traumatic for the main carer, as well as the person who has the brain injury. It is hoped to explore the changes and development people go through as they adjust to the role of carer, and the impact on their coping abilities. This knowledge can then be used to identify helpful coping strategies and facilitate change in carers who are finding it more difficult to adjust to their new situation.

3. Why were you chosen?

You have been identified as the main carer for someone with acquired brain injury. The main carer is defined as the person who spends a significant amount of time with, or lives with, a person with an acquired brain injury.

4. Who is conducting the study?

The study is being conducted as a requirement of the Coventry University and University of Warwick Clinical Psychology Doctorate. As such, Teresa Deane, Trainee Clinical Psychologist, is conducting the study with supervision from Dr Stephen Joseph at the University of Warwick. It is anticipated that the study will be completed by May 2004.

5. What is involved?

Thank you for your interest in this study. If you agree to take part, you will be given a pack of questionnaires. It is not anticipated that these will take more than 15 minutes to complete. There will be a pre-paid envelope for their return. Participation is optional and you will be free to withdraw at any time without affecting the future care of the patient you are helping

Following the initial questionnaires a small number of people will be selected for interview. This will involve an interview lasting up to 1 hour in the individual's home or another convenient location. This will be audio taped to assist the researcher and will be destroyed at the end of the study.

Thank you for your time and considering participation in this study.

Teresa Deane
Trainee Clinical Psychologist

Answers to questions you may have:

1. Do I have to participate in the interview part of the study?

No, there is a section on the consent form for you to initial if you wish to be interviewed, if selected. You are under no obligation to agree to be interviewed. You are at liberty to change your mind and withdraw at any point during the study.

2. What are the risks or benefits of taking part?

It is not anticipated that there will be any ill effects from participating in this research, however, it may draw attention to possible difficulties that you are experiencing. Details will be provided of how to receive help in that situation. It is not anticipated that there will be large personal benefits to taking part, except to realise how well you have adjusted and are managing. It is hoped that the benefits will be wider, to help people in a similar situation in the future.

It may be helpful for you to discuss your participation with the person that you are caring for. Although the study concerns you and how you have changed and are coping; these changes are a result of the brain injury they received.

You will be told if new information about this study becomes available which might affect your willingness to take part. If at any time the researcher considers it in your best interest, they will withdraw you from the study. They will explain the reasons and arrange for any support you are receiving to continue.

3. What if you have concerns regarding the study?

If you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you. In the first instance, contact one of the study supervisors to discuss your concerns.

4. Who will know you are taking part in the study?

All the information that is collected about you during the course of the research will be kept strictly confidential. Any information about you, apart from details required for correspondence, will be anonymised so that you cannot be identified by it. As you are not an identified patient, your GP will not be informed of your participation, however, if the researcher believes that the information provided places yourself or anyone else at risk, they will have a duty to share this information with the relevant professionals.

5. Ethical approval

Warwickshire Research Ethics Committee has approved this study.

6. The results of the study

It is hoped that the results of the study will be published in relevant journals. A copy of the results will be available to you on request from the main researcher.

Places to seek further support:

If you have any questions or queries regarding the study, please contact the researcher or supervisors:

Researcher: Teresa Deane

Supervisors: Stephen Joseph (Research Tutor) and Delia Cushway (Course Director)

At:

Clinical Psychology Doctorate

Health and Social Sciences

Coventry University

Priory Street

Coventry

CV1 5BF

024 7688 7806

The sole purpose of this study is for research reasons only and will not lead directly to any changes in your present or future service delivery. If participating in this study has led you to identify difficulties you are experiencing that you would like assistance with you can contact your GP or any of the following organisations may be able to assist you:

**British Association for Counselling
and Psychotherapy**

1 Regent Place

Rugby

Warwickshire

0870 443 5252

www.bacp.co.uk

British Psychological Society

St Andrews House

48 Princess Road East

Leicester

LE1 7DR

0116 254 9568

www.bps.org.uk

Your local Headway branch:

www.headway.org.uk

Headway Coventry and Warwickshire

Koco Building,

5 Arches Estate,

Spon End,

Coventry

CV1 3JQ

024 7667 5455

Coventry Carers Centre

3 City Arcades

Coventry

CV1 3HX

02407663 2972

Appendix D - Consent Forms

- **Consent Form A for questionnaire study**
- **Consent Form B for interview Study**

Programme Director
Doctorate Course in Clinical Psychology
Dr Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)
School of Health and Social Sciences
Coventry University
Priory Street Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8300



Our ref

Your ref

Date

Version: 4
Date: 08.12.03
Patient Information Number:

CONSENT FORM A

Psychological Experiences of Carers of People with Acquired Brain Injury

Researcher: Teresa Deane

Supervisors: Dr Stephen Joseph
Research Tutor
University of Warwick
(024) 7652 8182

Dr Delia Cushway
Programme Director
Coventry University
(024) 7688 8769

Please initial boxes

1. I confirm that I have read and understood the information sheet dated 14.11.03 (version 4) for the above study.

☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care, or that of the person I help or legal rights being affected.

☐
3. I understand that a small number of people will be interviewed as part of the research. I agree to be interviewed, if I am selected. I have provided my contact details for this purpose only.

☐

4. I understand that the information I provide will be treated with the strictest confidence, however, if the researcher believes that the information provided places myself or anyone else at risk, she will have a duty to share this information with the relevant professionals.

☐

5. I agree to take part in the above study.

☐

Address:

Telephone number:

<hr/>	<hr/>	<hr/>
Name of Participant	Date	Signature

<hr/>	<hr/>	<hr/>
Researcher	Date	Signature

1 for participant; 1 for researcher

Programme Director
Doctorate Course in Clinical Psychology
Dr Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)
School of Health and Social Sciences
Coventry University
Priory Street Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8300



Version: 3
Date: 14.11.03
Patient Information Number:

Our ref

Your ref

Date

CONSENT FORM B

Psychological Experiences of Carers of People with Acquired Brain Injury

Researcher: Teresa Deane

Supervisors: Dr Stephen Joseph
Research Tutor
University of Warwick
(024) 7652 8182

Dr Delia Cushway
Programme Director
Coventry University
(024) 7688 8769

Please initial boxes

- 1. I have discussed this study with the person I care for, who has agreed to my participation ☐
- 2. I give consent for the interview to be audio recorded. ☐
- 3. I understand that the information I provide will be treated with the strictest confidence, however, if the researcher believes that the information provided places myself or anyone else at risk, she will have a duty to share this information with the relevant professionals. ☐
- 4. I agree to be interviewed. ☐

Name of Patient

Date

Signature

Researcher
1 for patient; 1 for researcher

Date

Signature

Appendix E – Participant Characteristics

Means, standard deviations (S D) and range for carer characteristics

	Mean	S D	Range
Participant age	57.69	10.27	37-78
Age of person cared for	57.58	21.76	9-88
Time since injury (months)	82.76	73.15	6-288

Frequencies and percentages for carer's circumstances

	Frequency	Percentage
<i>Gender of carer</i>		
Male	5	13.9
Female	31	86.1
<i>Gender of person cared for</i>		
Male	29	80.6
Female	7	19.4
<i>Relation</i>		
Wife	16	44.4
Husband	3	8.3
Mother (inc. step-mother)	8	22.2
Father	1	2.8
Daughter (inc. daughter-in-law)	4	11.1
Son	1	2.8
Sister	1	2.8
<i>Injury Sustained</i>		
Traumatic brain injury	6	16.7
Stroke	21	58.3
Haemorrhage	3	8.3
Other	6	16.8
<i>Support Provided</i>		
Personal care	2	5.6
Emotional support	2	5.6
Activities of daily living	3	8.3
Combination	29	80.6
<i>Others at home</i>		
Spouse/ partner	6	16.7
Child	9	25
Spouse and child	3	8.3
Parent	1	2.8
No-one	17	47.2
<i>Support Received</i>		
Charity	6	16.7
Carers	6	16.7
Friends/family	3	8.3
Combination	3	8.3
None	6	16.7

Appendix F – Interview Schedule

1. Can you tell me a little about what life is like for you?
2. How is daily life different, what has changed?
Prompts: Work, home life, relationships, social life/support
3. How would you describe yourself?
Prompts: Personal characteristics,
how would someone else describe you?
4. Has this changed? How?
Prompts: Do you feel different, e.g. happy, sad, angry?
Do you think about things differently, do you have thoughts you've
never had before?
5. Have other's views of you changed?
Prompts: family members, friends
6. What help and support do you provide for _____? Does anyone
else help?
Prompts: personal care, organisational, emotional
7. How has this affected your relationship with them? Other people?
Prompts: how do you spend time together? Who do you get emotional
support from?
8. Have your views/beliefs about the wider world changed?
9. What are your thoughts about the future? Have these changed?
10. Can you think of anything that may have influenced these changes?
Particular incidents/attitudes?
11. What helps you cope? Personal resources, strategies
helpful/less helpful
12. Is there anything else you would like to tell me?

Appendix G – Examples of Analysis

- **Example of initial notes in left-hand margin**
- **Example of initial notes transformed into succinct phrases**
- **Example of cluster of emerging theme with participant phrases**
- **Example of identification of themes in other transcripts**

Example of initial notes in left-hand margin

<p><i>Like a child</i> <i>Have to tell husband what to do</i> <i>Always no</i> <i>Right way to ask</i></p> <p><i>More difficult in the first place, not so now</i></p> <p><i>Bossing someone around</i> <i>Husband – child</i> <i>Dynamics</i></p> <p><i>Controlling everything</i></p> <p><i>Always been bit of a planner</i> <i>Controlling streak</i> <i>Things to be sorted</i></p> <p><i>Didn't expect to take over</i> <i>Completely responsible</i></p> <p><i>Always looked after finances</i> <i>Relationship changes</i></p> <p><i>Have to remind him (like a child)</i></p> <p><i>Organise every bit of day</i> <i>In control, but not appearing to be</i> <i>More difficult</i></p>	<p>P like you would to a child, "it's time for you to go and have a shower, have you had a shower yet", no, which it's always no, right ok, well "I'll go and have a shower and then you can have a shower", but I've not found that difficult, the hardest bit about it was, um, having to tell him to do it in the first place, because you feel like you're bossing someone around, and it's your husband, not your child. It just changes the dynamics a little bit, you know</p> <p>I Mmmm</p> <p>and I have to say, I do feel quite often that, um, it's as if I'm controlling everything. I've always been a bit of a planner, as I've just said, and I do have this controlling streak anyway, I like things to be sorted and I like to know it's going alright, but I never expected to have to take over completely, you know the day to day little things, the personal things, um, finances and stuff like that, I always did that, so a lot of things didn't change, it's the relationship thing that changes as well, because you have remind him to have a shower and , he doesn't remember to have, but you just have to organise just about every little bit of the day, but, to a point you've got to try to make it that you're not doing that, and that's the hard bit</p>
---	--

Example of initial notes transformed into succinct phrases

P	like you would to a child, "it's time for you to go and have a shower, have you had a shower yet", no, which it's always no, right ok, well "I'll go and have a shower and then you can have a shower", but I've not found that difficult, the hardest bit about it was, um, having to tell him to do it in the first place, because you feel like you're bossing someone around, and it's your husband, not your child. It just changes the dynamics a little bit, you know	<i>Husband – child Responsibility Continuous Strategy Change over time Being responsible Husband – child Relationship Dynamics</i>
I	Mmmm	
P	and I have to say, I do feel quite often that, um, it's as if I'm controlling everything. I've always been a bit of a planner, as I've just said, and I do have this controlling streak anyway, I like things to be sorted and I like to know it's going alright, but I never expected to have to take over completely, you know the day to day little things, the personal things, um, finances and stuff like that, I always did that, so a lot of things didn't change, it's the relationship thing that changes as well, because you have remind him to have a shower and , he doesn't remember to have, but you just have to organise just about every little bit of the day, but, to a point you've got to try to make it that you're not doing that, and that's the hard bit	<i>In control Planner - personality Controlling - personality Previous coping Complete responsibility Previous role Relationship changes Responsibility Organisation Coping Strategy Difficult</i>

Example of cluster of emerging theme with participant phrases

Prior personality/ previous life

Succinct Phrase	Phrase with page and line identifier
Planner – part of personality	1.36 then I'm one of life's little planners, so it's all worked out quite nicely in a lot of ways
Importance of work	2.25 I've always been a worker, supporting R's business, managing your house, managing your child, managing your job, all very nicely worked out, it was a doddle really
Coper – part of personality	3.9 I am a big coper, I have to say, I do, I just get on with things really
Planner – part of personality	3.34 I've always been a bit of a planner, as I've just said
Controlling – part of personality	3.35 I do have this controlling streak anyway
Patience – part of personality	5.37 I think that makes a big difference, I have got loads of patience
Usefulness of job in preparation	7.14 but I have to say, again, in some ways, it's almost like you've been in practice for years on end because I worked at H [building society], and um,
Previous coping	7.16 you're dealing with people face to face and money issues, believe you me, can upset people, and you have to learn to cope with it, and you have to, you know whether you like it or not you just have strategies to deal with stroppy people
Planner – part of personality	9.32 everything has to be really planned basically, which suits me 'cause I'm a planner

Example of identification of themes in other transcripts

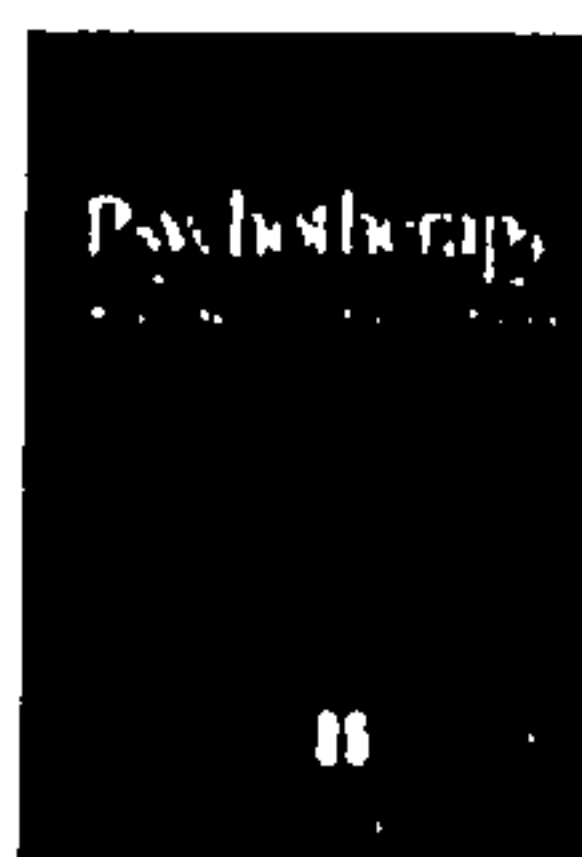
P	I mean I will be honest I've been through terrible stages of, I've found now with the medical profession, they don't tell you everything, and you have to, you have to fight such battles with them, to get the right medication, or the right information, or, and the onus is very much on, you know, A about his medication, and myself just checking it out and making sure and that never occurred to me before, I thought you were ill, I thought you were looked after, you were, people gave you medication, and, for your best interests, I don't find that now, although the medical profession have been wonderful and they've kept him alive, they've sort of almost, said well, we've kept you alive, you go and sort out your medication, you know, epilepsy a minor little thing that, you know, happens, and as regards people telling me that that might be a factor, nobody's ever, ever told me, you know, and I'm the sort of person, I like to know, I don't like things coming out of the blue at me, and just er, you know, so I've learnt a lot through that experience, as well,	<i>Struggle alone</i> <i>Self-reliance</i> <i>Self-reliance</i> <i>Expectations</i> <i>Changed expectations</i> <i>Previous Personality</i> <i>Change to coping</i>
---	---	---

Example of incorporation of sub-themes

Maintaining Self	Maintaining self Self-reliance
Use of coping	Developing coping strategies Planning and routine Gathering knowledge

Appendix H – Instructions for Authors

- **Psychotherapy: Theory, Research, Practice, Training**
- **Brain Injury**
- **Clinical Psychology**



Psychotherapy: Theory, Research, Practice, Training

Manuscript Submission Guidelines

Psychotherapy: Theory/Research/Practice/Training publishes a wide variety of articles relevant to the field of psychotherapy. The journal strives to foster interactions among training, practice, theory, and research, as all are essential to psychotherapy. Authors are asked to submit theoretical contributions, research studies, novel ideas, and the controversial, as well as examples of practice-relevant issues that would stimulate other theorists, researchers, and/or practitioners. The journal includes the widest scope of orientations to inform its readers.

Manuscripts

Manuscripts should be accompanied by an abstract of no more than 120 words according to the style specified in the *Publication Manual of the American Psychological Association* (5th ed.) and must also conform to the guidelines for the use of nonsexist language as promulgated by the American Psychological Association. Original color figures can be printed in color at the editor's discretion and provided the author agrees to pay half of the associated production costs; an estimate of these costs is available from the APA production office on request.

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Incoming Editor
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College Park, MD 20742-4411



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This journal covers all aspects of brain injury from basic science, neurological techniques and outcomes to vocational aspects, with studies of rehabilitation and outcome of both patients and their families. It addresses both adult and paediatric issues and it embraces issues such as family and peer relationships, effects of alcohol and drugs, communication problems and management techniques and creating new programmes. **Brain Injury** uses case studies to illustrate different approaches to a subject, and provides a forum for the appraisal of theories which may influence future research. **Brain Injury** is the official research journal of the *International Brain Injury Association*.

This journal is now available on line.

Contacting the Editors:

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$$61 + 5h + q$$

$$3n + 3yz^2$$

But: $\frac{a}{b} + \frac{c}{d} + \frac{a}{d}$

$$P = (a^2 + b^2)(c^2 + d^2)$$

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1. To a book:

38. KOLB, B. and WISHAW, I. Q.: *Fundamentals of human neuropsychology* (New York: WH Freeman), 1990.

7. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders* (4th edn). (Washington, DC: American Psychiatric Association), 1994.

2. To a chapter in a book:

30. WILLER, B., LINN, R. and ALLEN, K.: Community integration and barriers to integration for individuals with brain injury. In: M. A. J. Finlayson and S. Garner (editors) *Brain Injury*

Rehabilitation: clinical considerations (Baltimore, MD: Williams and Wilkins), pp. 355-375, 1993.

3. To an article in a journal:

32. MASSON, F., MAURETTE, P., SALIM, L.R. *et al.*: Prevalence of impairments 5 years after a head injury and their relationship with disabilities and outcome. *Brain Injury*, 10: 487-497, 1996

4. To a technical report and to unpublished literature

42. BURNHAM, C.A. and ANDERSON, T.H., 1991, Learning to sew on a button by reading a procedural text. CSR Technical Report, No. 543, Center for the Study of Reading, University of Illinois at Urbana-Champaign. ERIC ED 332 157.

31. CLARK, C.M. and LAMPERT, M., 1985, What knowledge is of most worth to teachers? Insights from studies of teacher thinking. Paper presented at the annual meeting of the American Educational Research Association (College of Education, Michigan State University, East Lansing). ERIC ED 266 109.

5. Reference to a newspaper or magazine

29. RICHARDS, H., 1996, Republican lite? *The Times Higher Education Supplement*, 1 November, 16.

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24. <http://acsinfo.acs.org/instruct/instruct.html>

7. Reference to a personal communication

12. BRANNEN, J. (1996) Personal communication.

8. Reference to a case in law

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34. *Miranda v. Arizona* 1974

9. Reference to government legislation

34. US Congress, Senate Committee on Foreign Relations, 1956, *The Mutual Security Act of 1956*, 84th Congress, second session, report 2273.

8. US Congress, House Committee on Banking & Currency, 1945, *Bretton Woods Agreements Act: Hearings on HR 3314*, 79th Congress, first session, report 452.

6. United Kingdom Parliament, Committee on the Working of the Monetary System [Radcliffe Committee], 1960, *Principal Memoranda of Evidence*, vol. 2, Cmd 1958.

31. United Nations General Assembly, Secretariat for Economic Affairs, 1951, *Methods of Financing Economic Development in Less Developed Countries*, report II B 2.

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